The School and Social Experiences of Tourette Syndrome through the First-Person Perspective of Youth: A Theatre-Based Approach to Community-Based Research

by

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Abstract

Tourette Syndrome Plus (TS+) is a “neuropsychiatric or brain-based condition that causes people who have it to make involuntary sounds or movements called tics” (Tourette Canada, n. d., para. 1). Individuals with TS+ may also have a number of associated disorders such as OCD, ADHD, and Anxiety Disorder. Community-based research and popular theatre activities were used in this research to explore social and educational issues that may arise for youth with TS+ aged 14-15. The topic of TS+ is viewed through social models of disability and utilizes a transformative worldview. This research explores the role of theatre in building self-advocacy skills, increasing self-confidence, and/or improving upon socialization skills for youth with TS+. Youth with TS+ participated in weekly theatre sessions to create a script that demonstrated their experiences with TS+. This script was performed to an audience of TS+ community members, as well as members of the University of Alberta community. The collaboratively created script, titled “Ditched,” follows the character of Thomas as he engages with the notions of bullying, popularity, and exclusion. This research found that youth with TS+ may carry with them internalized loneliness, guilt, and/or shame for having TS+. These internalized feelings may manifest in youths’ withdrawal from social situations, and may also impact youths’ self-confidence and their ability to self-advocate. This research concludes that popular theatre provides a powerful space for youth with TS+ to express internalized feelings, and build self-advocacy, self-confidence, and socialization skills. Being that the researcher is also an adult with TS+, the study conflates the youth participants’ present experiences of TS+ with the researcher’s past and present experiences of TS+.

"The difference between humans and other animals resides in the fact that we are capable of being theatre. Some of us 'make' theatre – all of us 'are' theatre."

(Augusto Boal, 1998, p. 7)

This study is dedicated to everybody with Tourette Syndrome, as well as their families and their friends. May we continue to educate others in an effort to override stigmatization.

This study is also dedicated to my family, who have always supported me and loved me without reservation. My strength is the result of your efforts.

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Chapter 1

Introduction

Study Overview

This research study uses a theatre-based approach to community-based research to explore the social impact of Tourette Syndrome Plus (TS+) on youth ages 14-15. As an individual with TS+, I approached this research with an understanding of the physical and psychological impact that TS+ may have on a person, as well as the social ramifications of TS+ that can negatively impact a person's mental well being. In addition to having an intimate understanding of the experience of TS+, I also approached the research with a wealth of theatrical experience – both as a former stage actor and director, and as a trained drama instructor. The combining of TS+ and theatre has played an important role in shaping my personal identity. This research study grew out of my desire to work with youth with TS+, to provide those youth a safe mental space to better understand themselves as individuals with TS+, and to provide them with a safe physical space to inhabit, in which they could express their understandings to others.

In using a theatre-based approach, the research study sought to explore a tacit understanding (Polanyi, 1966) of the experiences of TS+ through the creation of a popular theatre[1] performance. Theatre allowed the research to also get a glimpse into audience members' experiences, as what audience members took from the performance was based on what they already understood about themselves (Merleau-Ponty, 1962), and what they thought they understood about others.

The design and approach to this research study were guided by the questions:

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[1] The term Popular Theatre refers to the creation of theatre about subjects that hold political or social importance within a community. Prentki & Selman (2000) assert, "popular theatre works to facilitate independence, to assist communities in a

- *What are the experiences of TS+ for youth aged 14-15?*
- *What experiences impact youth with TS+?*
- *What are the social ramifications of these experiences?*
- *How do these experiences affect the youths' social status and educational encounters?*

Through the exploration of these questions, youth participants and I intertwined our shared, yet unique, experiences of TS+, allowing the research to become a "product of the interaction between site and researcher" (Lincoln & Guba, 1988, p. 8), in which I see "site" as the experiences of the youth participants. Through the intertwining of shared experiences, a generalized, fictitious representation of TS+ was created.

Narrative: Genesis – The Creation of Sound

> *At the age of nine I produced the first vocal tic that I remember producing. I remember it with vivid recollection.*
>
> *I was lying on the carpeting in the basement of my childhood home. The carpet was beige, rough, and old. It had the damp, musty smell that accompanies old carpeting in basements.*
>
> *I was lying on this carpet, feeling the scratchy roughness of it on my skin. It was a weekday evening and I was supposed to be doing my homework, but instead I had snuck into the family room to watch television.*

My first vocal tic was an echo of a laugh – cascading upward from my throat and coming to rest in a high pitched, elongated 'humph' in my nasal cavity
It felt good! It felt…right!

A sensation, like creeping fire throughout my body, urged me to repeat the sound.

At first I playfully revelled in the sound, exploring the vibratory sensations of the high pitched sound in my nose. I played with the pitch and possibility of this sound – a sound I had never imagined I would (or could) produce.

After several iterations, the relationship between me and the sound shifted. I was tired of it. I wanted to stop the sound – but the sound wouldn't stop.

The sound became demanding –

"MAKE THE SOUND IN YOUR NOSTRIL!" it demanded
    i ticced
"NOT THE RIGHT NOSTRIL – ONLY THE LEFT NOSTRIL!"
    i ticced
"HIGHER IN THE LEFT NOSTRIL!"
    i ticced
"NOW SNIFF AFTERWARD!"
    i ticced

The demands came faster

"HIGHER IN THE NOSTRIL!"

tic

"HIGH IN THE LEFT THEN LOW IN THE RIGHT!"

tic - tic

"NOW SNIFF"

tic – tic - sniff

"WRONG! LEFT-RIGHT-LEFT-SNIFF!"

tic – tic – tic – sniff

"AGAIN!"

tic – tic – tic – sniff

"AGAIN!"

tic – tic – tic – sniff

"GOOD WORK!"

That was my first vocal tic. It came in private, but it would soon become my public personae.

Tourette Syndrome – The Experience of a Tic

This is the first vocal tic that I remember producing, but it may not have been my first tic. It may not have even been the first sign of TS+. In my youth I found it difficult to sit still, but this was just seen as me being a rambunctious young boy. My physical tics had not yet expressed themselves in random patterns, just leg shaking and wiggling if I had to sit for long periods of time – again both of these being quite normal in young boys. Another early sign of the plus (+) in my TS+[2] may have been my persistent day dreaming in class. I have memories of staring out the classroom window, dreaming stories. I believe I may have even been given a seat across the room on the opposite side of the window in my elementary school for that very reason – I even believe a report card sits in a moldy cardboard box in my parents' basement with a comment scorning my inability to focus.

The examples provided above may be indicators of early ADHD in my youth, or they may have been examples of a young boy who did not want to be in school. These memories are thirty years old, and I am viewing them through the lens of my past and present experiences with TS+. Whether these memories are factual representations of thirty years ago, or have been fictionalized, the truth at the heart of the story remains intact – as a youth I expressed signs of TS+ and these signs, for various reasons, went unnoticed.

Tourette Syndrome is a "neuropsychiatric or brain-based condition that causes people who have it to make involuntary sounds and movements called tics" (Tourette Canada, n. d., para. 1). For individuals with TS+, tics are prefaced by something called a premonitory urge,

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[2] In is estimated that 90% of individuals with Tourette Syndrome experience associated disorders such as Obsessive-Compulsive Disorder (OCD), Attention Deficit Hyperactive Disorder (ADHD), Anxiety Disorder, Neurological Storms, Learning Disabilities, Sleep Disorders, Executive Dysfunction (which impacts an individual's planning, organizing, and strategizing abilities), and more (Tourette Canada, n. d.). In 1991, the term Tourette Syndrome Plus (TS+) was introduced (Packer, n. d.) to account for these associated disorders. As the majority of individuals with Tourette Syndrome have one or more associated disorder(s) (Tourette Canada, n. d.), throughout this thesis the term TS+ will be used exclusively to include those with associated disorders and those without associated disorders.

which can be described as “an unpleasant sensation or vague feeling of discomfort” (Tourette Canada, n. d., para. 5). Within a tic, there is a sense of searching for perfection. A tic must occur in a precise area of the body (vocal and/or motor), at a precise moment. This may or may not (but often does) involve the holding in or letting out of breath for a precise length of time at a precise moment within the tic. I equate this search for perfection within a tic to that of asking somebody to scratch an itch on your back – the itch itself being the premonitory urge. When the scratcher approaches the itch, the itch can move, intensify, and/or split into two (or more) separate itches. In the way that the scratcher may intensify efforts to search for the itch, individuals with TS+ may intensify efforts to search for perfection in the tic, thereby getting caught in what is colloquially referred to as a “tic attack”[3]– the repetition of a certain pattern of sounds and/or movements until the desired pattern is achieved.

As an adult with TS+, I have an intimate understanding of the social implications of having vocal and motor tics. Likewise, I have an intimate understanding of the personal struggles involved in presenting oneself as “normal” in a society in which random vocal and physical outbursts are not “normal.” As an adult, I have developed strategies that, to varying degrees, are able to mask my vocal and physical tics. I have also discovered strategies to work around the associated disorders I experience with my TS+ (which in my case are ADHD, OCD, Anxiety Disorder, and Neurological Storms). Although I am now able to engage strategies to lessen the social impacts of my TS+, as a youth I did not have these strategies, nor did I have an advocate to speak on my behalf, which led to feelings of being socially ostracized within my elementary and high school communities. Being ostracized, I

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[3] While individuals with TS+ commonly use the term “tic attack” as a colloquialism to describe a pattern of persistent and localized tics (ex. continued pattern of blinking or winking that may last for several minutes), the term “tic attack” is also used to describe a situation called a tic status – also sometimes referred to as “ticcing fits” (Sachdev, Chee, & Wilson, 1996; Collicott et al., 2013; Thom, 2013; Water, 2015). In tic status, the individual with TS+ experiences full body tics that may mimic a seizure activity. This tic status (or “ticcing fit”) can last from several minutes to several hours. A very small percentage of individuals with TS+ experience tic status.

chose to withdraw from the social culture of my school – this included withdrawing from lessons. I did not ask questions in class and I did not engage with group work. During my early high school years, I tried my best to become invisible.

Narrative: The Challenge – Gaining Awareness

> *I was in grade two when I was made aware of the fact that I couldn't sit still. It had never occurred to me that constantly shaking a leg up and down was not considered 'normal.'*
>
> *However, this lack of normalcy was not lost on my classmate.*
>
> *"Can't you just sit still?" he asked, more for the benefit of those around me than for me.*
>
> *I had never wondered if I could; in fact, I had never realized that I didn't sit still. I hadn't yet developed the tell-tale vocal tic (that wouldn't come for another few years), but, unbeknownst to my classmate or me, Tourette Syndrome was already with me.*
>
> *"I'll betcha a quarter you can't sit still for one full minute!"*
>
> *The challenge was on.*
>
> *I sat in my chair, stared straight down at my desk, and tensed every muscle in my body*

– forcing my limbs into submission, willing my eyes not to blink. It was exhausting.

"See, told ya you couldn't do it! You owe me a quarter!"

I had failed the test.

"That was a stupid challenge anyway, what did it even prove?" I thought. But somewhere, deep inside, I was aware of just how important that challenge had been.

My Personal Experiences with Tourette Syndrome

I grew up in the small town of Bishop's Falls – a town of 3500 people located in the middle of Newfoundland, Canada. I entered grade two in 1985, when little was known globally about TS+, and nothing was known about it in Bishop's Falls. While currently my vocal and motor tics have subsided to a manageable level, as they do for a large number of adults with TS+ (although associated disorders do not diminish or disappear) (Turtle & Robertson, 2008; Tourette Canada, n. d.; Packer, n. d.; Grace & Russell, 2005; Conelea, et al., 2010), as a youth my tics were out of control. Screeching sounds, loud grunting noises, strange facial movements, and flailing arms and shoulders were but a few of the tics that inhabited my body as a youth. Due to the fact that nobody in my hometown knew anything about TS+, and doctors were unable to provide me with a diagnosis, I was often accused of faking my tics to gain attention or to disrupt lessons at school. On more than one occasion my desk was moved outside the classroom into the hallway; I was sent to the principal's office; I was threatened with suspension; and I was given detention – and this was just the negative response from my teachers. TS+ also negatively impacted my social interaction with peers. I was regularly teased, physically bullied, and often ostracized from normal social interactions. I knew I could not control the sounds and movements that I was making, but nobody believed me. I began to wonder why I could not control them, and what that would mean for me in the future.

In the tenth grade I joined my high school drama club. At first, the thought of standing on stage terrified me. I already felt that attention was overly focused on me (in a town of 3500 people, a kid who is constantly grunting and screaming while shrugging his shoulders and squishing his face is hard not to notice!), and the thought of explicitly asking for more attention terrified me. In addition, I had spent several years cultivating an aura of invisibility. Drama club was in direct opposition to this attempt at invisibility. However, despite all this fear, I joined the drama club for two reasons: Mr. G, the drama club facilitator; and Ro, a foreign exchange student from Switzerland who was staying at my house. Mr. G was a short man with long hair pulled back in a ponytail and wore overalls almost everyday. In my mind, he did not fit into the social fabric of the small town high school – and to me that was a good thing. In him I saw the ability to be accepted beyond difference. Ro wore ripped jeans, had shoulder length hair dyed bright red, and listened to punk music such as Sex Pistols and The Ramones. Added to this, he spoke with a strong Swiss German accent and refused to conform to the social rules of my small town. Ro and I joined the drama club together. Without his support, I probably would never have joined the drama club. This high school drama club provided me with my first opportunity to narrate my own story.

By joining the drama club, I learned something that many individuals with TS+ have also discovered; for many individuals with TS+, there is one activity that weakens the internal desire to tic. For some individuals with TS+, the activities are sports, music, or dancing, but for me it was theatre. Theatre was my way of saying, “If I am going to be on display, then I am going to choose how I am displayed.”

In 1996 I turned 20 years old and was finally diagnosed with Tourette Syndrome. The relief of having a diagnosis was somewhat weakened by the fact that my vocal and motor tics had already started to subside – the worst was behind me.

In 2010, at the age of 34, at the suggestion of an instructor, I researched Tourette Syndrome for an in-class presentation. It was then I learned that Tourette Syndrome is often accompanied by associated disorders. This was also when I learned that the term Tourette Syndrome Plus (TS+) was used to account for the presence of associated disorders. Suddenly my past episodes of anxiety attacks were explained and my difficulty with prolonged focus became clear. At the age of 34, I gained even further insight into the strange sounds and movements that I produced as a youth, as well as the anxiety that I had experienced since I was a child.

Narrative: Fog of Anxiety

> *When I was in elementary school, bedtime was 8:30 p.m. Every night at roughly 8:30, for about a year, a nightly ritual of tears, pleads, and screams played out between my parents and I.*
>
> *Every night, anxiety – growing to panic – inhabited my body. Like a fog that enveloped*

everything in its path, in the hours leading to bedtime my anxiety would begin its slow movement through my body. It would rise from my stomach, where it had been pooling since dinnertime, into my ribcage – constricting the balloon-like movements of my inter-costal muscles connecting each rib – restricting the deepening of breath.

It would envelop my neck and shoulders, tightening the sinuous ropy fibres of each muscle as it moved. As bedtime grew closer, this fog of anxiety would begin to fill my head – pooling in my brain, bringing with it quivering lips and leaking eyes.
At 8:30, the rising fog of anxiety would erupt – volcano-like – into an explosion of sheer panic.

The catalyst of this anxiety was the irrational correlation between bedtime and the death of both of my parents. I was convinced that if I slept, both of my parents would die in the night. In those moments, in my child-mind, this was not a possibility, it was not an irrational fear – it was a very real inevitable conclusion.

I was more than a child who wished to push his bedtime a little later. I was fighting to keep my parents alive.

This is my first recollection of anxiety!

Reflection on “Fog of Anxiety”

For me, anxiety is ever-present. Most days it flickers in the background, like a dim bulb. Other days it burns bright, shining the spotlight directly on me. However, I have learned to calm my anxiety through diet, exercise, and by avoiding my triggers. I have learned that eating certain foods, not getting enough exercise, depriving myself of sleep, and over-indulging in alcohol or caffeine can leave me prone to anxiety attacks. This awareness of my personal limitations has come from years of self-exploration, and from many experiences with anxiety attacks, which at times have been both emotionally taxing and socially embarrassing.

In the four years between learning about the disorders associated with Tourette Syndrome and the designing of this research study, I researched the topic of TS+, delivered presentations on the topic whenever possible, and became a member of the national and local TS+ community through Tourette Canada (formerly Tourette Syndrome Foundation of Canada). Through my research, presentations, and by joining the TS+ community I have come to not only understand myself better as an individual with a ‘hidden’ disability, but also gain comfort being myself.

Why Is This Research Necessary?

As previously mentioned, as an adult with TS+ I have developed techniques and strategies to mask my tics, as well as ways of working around my associated disorders. In addition to developing techniques and strategies, people have offered me opportunities to find a space of my own in the world and to take up that space with some degree of confidence and self-assurance. As a youth with TS+, I regressed into myself. I attempted to make myself smaller than my body. My breath became shallow. The sounds and movements that were in my control were small and doled out with careful precision. If at all avoidable, my gaze would never meet the gaze of another person. Until I found theatre and my high school drama club, I felt guilty at taking up space – unworthy of even the small spot of space that my body required. Until I found theatre and my high school drama club, I had never been invited to take up space; I had never even considered it a possibility.

In engaging with this research study, it was my desire to invite youth with TS+ to take up their space in the world. For me the space that I took up involved theatre. The youth participants of this study were in the process of discovering how they will choose to take up their space. I offered theatre as a space for the youth to explore, not because it is the best option, necessarily, but because it is an option that I (an adult with TS+ who has some understanding of their experiences with TS+) understand, and it is an option worthy of exploration. In taking up space within a piece of drama (presented in front of an audience), my hope was that youth participants would find their own spaces and fill those spaces with their own voices (both physically and metaphorically). In filling the spaces with their voices, I hoped that they might experience the power of having both their physical and metaphorical voices listened to by a caring and compassionate audience.

Youth with TS+ may have motor and vocal tics that make them stand out from others. Added to this is the fact that other associated disorders, such as OCD, ADHD, Anxiety Disorder, and Executive Dysfunction, can make it difficult to recognize and adhere to socially subscribed norms and patterns. Many of the youth with TS+, whom I met from across Canada prior to this research, expressed a desire to disappear in social settings, such as at school – the cruel irony being that it is hard to disappear when you make involuntary and seemingly random sounds and movements. This research is my invitation for youth with TS+ to take up space, and in the process, I hoped that they might feel the transformational potential present within those spaces, and within their own voices.

Narrative: Ticcing Genius

When I was in grade 4 something strange started happening. I started making high-pitched sounds, and shrugging my shoulders uncontrollably.

It was frustrating! I must have driven my family crazy – loud noises, ritualistic movements. People would say, "Just stop it!" – but I couldn't. I couldn't stop and I didn't know why. I thought I might be insane, and that scared me.

I remember once, when I was in grade 5 or 6, I was having a day where my tics were pretty bad. My family had just finished supper – my mom and my sister were doing the dishes. It was just me and my dad at the table. Dad quietly leaned back in his chair, put his feet up on an empty chair, lit a cigarette, blew out a puff of smoke, and without looking at me, said, "I saw on the news yesterday that people who make noises, like the kind of noises that you make – well they say they're geniuses."

That was all he said. No discussion followed this remark, just silence. I don't know what intentions he had for saying that, or if he had even seen such a news report, but I took it to heart. The next day in class, when the teacher wrote math questions on the *board (Oh, how I hated math!) and asked students to raise their hand if they knew the answer, I attempted answers for almost every one of them, and I was right on every one of the questions that I attempted!*

From that day on, I knew I was smart…a genius even. My father had told me so.

Outline of Chapters

The introduction above, Chapter 1 of this thesis, examines my personal connection to the research, thus providing a personal rationale for why I view this research as important. I also offer a rationale for the significance of this research in a broader educational context. Chapter 2, which follows, reviews some of the available literature relevant to research with youth with TS+ and also develops a theoretical framework for this research study drawing on socially influenced approaches to disability and first-person perspectives of TS+. This research study is an exploration of the narrative experiences of youth with TS+ and in this sense engages with medical understandings of TS+ only in as far as they were contributing factors to the youths' narratives. In examining some of the literature available on socially influenced approaches to disability, this research study is able to better situate itself on the spectrum between a medical model and social model of disability.

Chapter 3 of this thesis examines the methodology and methods of this research study. It lays out the rationale behind this research study's transformative worldview, while also exploring the theoretical underpinnings of both community-based and theatre-based research. Chapter 3 continues in discussing the design of this research study, as well as the theatre, teaching, and audience engagement methods used during the community performance portion of the study.

Chapter 4 is a written representation of a script created by the youth and I for a sharing-celebration. This script was performed for the Tourette Syndrome and University of Alberta communities on March 14th, 2016. Included with the script of the live performance are transcripts of the video segments that were interspersed throughout the performance. Chapter 4 also discusses the background to how the script was created, describes the characters, and presents the discussion questions that were posed to the audience.

The 5th and final chapter of this thesis is my reflection on the process and product of the research study. This chapter reflects on the research study, taking into account such things as limitations of the study and the lessons learned. Chapter 5 also reflects on what participants and audience members may have taken away from the research, as well as what I have taken away from the research, including considerations around process and product in community-based research.

While my personal experiences of TS+ provide a framework for this research, it is important to also locate the experience of TS+ outside of myself. For that, I turn to the literature review, which explores various (adult and youth) first-person experiences of TS+, provides a definition of TS+ and its various associated disorders, and explores various socially influenced approaches to disability, which inform the social models of disability framework for this research study.

Chapter 2

Literature Review

The over-arching research questions posed for this research study were: *What are the experiences of TS+ for youth aged 14-15? What experiences impact youth with TS+? What are the social ramifications of these experiences? How do these experiences affect the youths' social status and educational experiences?* In order to engage with these questions, I conducted a literature review to discover how this research study fit within the existing TS+ literature. In addition, my review focused on literature regarding socially influenced approaches to disability. This research study on the first-person experiences of youth with TS+ used socially influenced approaches to disability to develop a theoretical framework or lens to inform the research design and through which the research with the youth was viewed. I also reviewed literature that involved first-person perspectives of youth who have experience of TS+, and specifically literature based in school or social contexts. These parameters were defined to retrieve literature relevant and pertinent to my research study.

A preliminary search on TS+ in several databases uncovered a plethora of literature written in academic journals about TS+ that did not directly relate to my research. For example, I uncovered a large amount of source material that approached the topic of TS+ from a strictly medical or parental perspective. Some of this unrelated literature did influence my research design. For example, Mason, Bannerjee, Eapen, Zeitlin, and Robertson's (1998) article *The Prevalence of Tourette Syndrome in a Mainstream School Population*, which was not based on first-person youth experiences of TS+, used questionnaires with parents, teachers, and students to conclude that there is a higher prevalence of TS+ in schools than previously suspected. While this article did not provide information about first-person experiences with TS+, it did provide knowledge regarding an increase in the prevalence of TS+ in schools. This knowledge helped to inform focus group discussions that took place during the research sessions.

TS+ literature that fit within my defined parameters of first-person experiences of youth in school or social contexts included four videos: *Spencer* (Golding & Bobula, n. d.), *Ethan* (Luftspring & Moscovici, n. d.), *Neil* (Croswell, n. d.), and *Teenage Tourettes Camp* (Scott, 2006); three children's books: *Hi I'm Adam: A Child's Book about Tourette Syndrome* (Buerhens, 1990), and *Tic Talk: Living with Tourette Syndrome: A 9-year-old boy's story in his own words* (Peters, 2009), *Ticcing Thomas: The World's Fastest Arm Flapper* (Bobula & Bobula, 2009); one biography: *Front of the Class: How Tourette Syndrome made me the Teacher I Never had* (Cohen & Wysocky, 2005); two doctoral dissertations: *Tourette Syndrome in Adolescence: How it impacts an adolescent's experience of their family, peers, school, self-concept and view of the future* (Happich, 2012), and *The experience of Stress in Children with Tourette Disorder: An Interpretive Phenomenological Examination from the Child's Perspective* (Lee, 2008); one interview: "An Interview with Susan Conners: An Educator's Observations about Living with and Education of others about Tourette's Syndrome" (Chamberlain, 2003); and one article: "Tics, Twitches, Tales: The Experiences of Gilles de la Tourette's Syndrome" (Turtle & Robertson, 2008).

Focusing on understanding TS+ through the first-person experiences of youth with TS+, and how TS+ impacts both social interactions and schooling, this chapter contextualizes the research study by first offering a description of TS+, followed by an exploration of the framework based on the socially influenced approaches to disability. The chapter concludes with an examination of the literature on first-person experience of TS+.

What is TS+?

As previously mentioned, TS+ is a “neuropsychiatric or brain-based condition that causes people who have it to make involuntary sounds or movements called tics” (Tourette Canada, n. d., para. 1). These tics can be motor (i.e., physical movements) or vocal (i.e., sounds and noises). Currently, research into TS+ shows prevalence rates at 1 in 100 people (or approximately 1% of the population) (Tourette Canada, n. d.).

Tics can be simple, involving one sound or movement (e.g. sniffing, throat clearing, blinking, etc.), or complex, involving several muscle groups or sounds (e.g. spinning, hopping, etc.). Complex tics may also fall into one of two areas: praxias and lalias. The suffix “praxia” refers to complex motor tics such as copropraxia (the involuntary use of inappropriate actions and gestures), echopraxia (the involuntary repetition of actions and gestures used by another person), and palipraxia (the involuntary repetition of a person’s own actions and gestures). The suffix “lalia” refers to complex vocal tics such as coprolalia (the involuntary utterance of inappropriate words or phrases), echolalia (the involuntary repetition of phrases or words spoken by another person), and palilalia (the involuntary repetition of a person’s own words and phrases). While “praxias” and “lalias” gain a lot of media attention they are rare, affecting only 10% of all individuals with TS+ (Tourette Canada, n. d.).

In 1991, the term Tourette Syndrome Plus (TS+) was introduced (Packer, n. d.) to account for associated disorders, which occur in approximately 90% of individuals with Tourette Syndrome (Tourette Canada, n. d.). These associated disorders may include Attention Deficit Hyperactive Disorder (ADHD), Obsessive-Compulsive Disorder (OCD), Anxiety and Mood Disorders, Executive Dysfunction (which impacts an individual’s planning, organizing, and strategizing abilities), Sleep Disorders, Learning Disabilities, Neurological Storms (or rage attacks), and others (Tourette Canada, n. d.).

Medical literature indicates that a large percentage of individuals with TS+ will experience a decline in tic severity in late teens to early twenties (Hassan & Cavanna, 2012; Cohen, Leckman, & Bloch, 2013; Tourette Canada, n. d.). Taking this into account, the original design of this research study focused on youth aged 13 to 18. By focusing on this age range, the study sought to gain insights into youths' experiences during the peak severity of tics, and also to highlight youths' experiences of TS+ in secondary schools. It is important to note that while medical literature indicates a decline in tic severity in the late teens to early twenties, the literature does not indicate a decline in associated disorders.

Stress and its impacts on TS+. An issue that I was keenly aware of throughout this research study was the impact that stress can have on individuals with TS+. From my personal experience, I was aware that stress had the potential to exacerbate ADHD tendencies, increase anxiety, and bring about increased vocal and motor tics. This personal observation was corroborated in the doctoral dissertations of Stephanie C. Lee (2008) and Robert Happich (2012). Similar to my research study, Lee (2008) and Happich (2012) approach their doctoral research on youth with TS+ from a qualitative perspective (even calling for further qualitative research to be undertaken in the field of TS+). Both scholars point to the negative impact that stress can have on youth participants.

While I had personal experience with the negative impacts of stress on TS+, these dissertations illuminated the "double-edged sword" (Happich, 2012, p. 54) of stress and TS+. Happich (2012) notes the participants of his study shared the negative impacts of stress as a common experience: “participants experienced stress related to TS in experiences with their family, peers, at school and other social settings” (p. 54).

Lee (2008), whose research study focused on the experience of stress on TS+, noted “other negative psychosocial effects” (p. 24) that arose from stressful social and school based experiences of individuals with TS+. Some of the negative psychosocial effects noted by Lee included: “being viewed as irritating or disruptive by teachers…being the target of jokes…having few close friends [or] lacking friends in general…feeling lonely…feeling ‘socially inept’ and/or ‘stupid’…struggling with low self-esteem…disliking school…depression and even suicidal thoughts” (p.24).

Happich’s and Lee’s explorations of stress as a trigger of TS+ symptoms highlights the feedback loop that makes TS+ especially challenging. Tics and associated disorders create behaviours that are viewed as being beyond the social normative realm, which in turn brings negative focus from friends, classmates, and teachers. This negative focus creates stress as the individual with TS+ may attempt to suppress tics and behaviours not deemed “normal.”[4] This stress may lead to an increase in tics and associated disorder(s), which in turn increases the negative focus from friends, classmates, and teachers – so the cycle continues. Heading into the research, it was important for me to be aware of the negative impacts of stress. In designing the sessions, in engaging in dialogue, and in preparing the youth for the final performance, I was aware of the potential negative impacts of stress and therefore I attempted to diffuse stressful situations as much as possible.

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[4] While it is possible for an individual with TS+ to suppress their tics, this is not possible for long periods of time. Many first-person reports from individuals with TS+ speak to a tension or stress that builds within the body when tics are suppressed. When the individual with TS+ is able to release their tics, the tics will usually come with greater ferocity. This has also been my personal experience with the suppression of tics.

Social Models of Disability – From Inception to Practice

The social model of disability arose from the work of the Union of the Physically Impaired Against Segregation (UPIAS), which was started in Britain in the mid 1970s (Hunt, 2001). The UPIAS was started when Paul Hunt, a disability activist, published a letter in the local newspaper in Leeds, UK inviting individuals with disabilities to join a group to explore what Hunt saw as the unfair living and working conditions of individuals with disabilities in the UK at that time (Hunt, 2001). In 1976, the UPIAS released a statement that outlined what they saw as the social oppression of individuals with physical impairments, and in doing so they laid the groundwork for the social model of disability. The document stated:

> In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from the full participation in society. Disabled people are therefore an oppressed group in society. (UPIAS, 1976, p. 3)

This UPIAS document defined the term “impairment” as “lacking all or part of a limb, or having a defective limb, organism or mechanism of the body” (UPIAS, 1976, p. 4), and defined the term “disability” as “restriction of activity caused by a contemporary social organization which takes little or no account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities” (UPIAS, 1976, p. 4). In separating the definitions of “impairment” and “disability” to represent physical barriers and social barriers, respectively, the UPIAS was able to claim that “physical disability [was] therefore a particular form of social oppression” (UPIAS, 1976, p. 4). Based on the work of the UPIAS, Mike Oliver (1981) coined the phrase "social model of disability" in his essay *A New Model of the Social Work in Relation to Disability*.[5]

The scope of disabilities included in the early UPIAS meetings was narrow – focusing only on physical impairments. In the years since the formation of the UPIAS, many other branches of disability studies have formed, including Mad Studies – pioneered by "mental health survivors, activists and educators" (Beresford, 2014, para. 2) such as David Reville, Geoffrey Reaume, Kathryn Church, and Brenda LeFrançois. Mad Studies derives from a social model approach, stating that it uses "humanitarian, holistic perspectives where people are not reduced to symptoms but understood within the social and economic context of the society in which they live" (Menzies, LeFrançois, & Reaume, 2013, p. 2). Further mirroring the UPIAS, the exploration of Mad Studies arises from the first-person experiences of individuals with mental disabilities, as opposed to the second-person experiences of medical professionals, claiming to take "as its principal source, inspiration, and raison d'être the subjectivities, embodiments, words, experiences, and aspirations of those among us whose lives have collided with the powers of institutional psychiatry" (Menzies, LeFrançois, & Reaume, 2013, p. 13-14). Since Mad Studies arises from the same experientially driven social fabric as the UPIAS, it has the potential to encounter some of the same arguments as encountered by the UPIAS; by rejecting the medical model, the benefits of diagnosis and medical interventions to the individual are disputed.

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[5] The social model of disability was created and coined as a British concept that was later adopted and adapted within North American contexts. There are a couple of key distinctions between the British social model and the North American social model. Whereas the British model views individuals with disabilities as "an oppressed social group" (UPIAS, 1976, p. 3), the North American model views individuals with disabilities as "a minority group" (Shakespeare & Watson, 2002, p. 4; Hahn, 1985, p. 1). In terms of language, the British social model uses the terminology "disabled people," to acknowledge that individuals are (dis)abled by society, whereas the North American social model, influenced by the "people-first" language, uses the terminology "people with a disability" (Martin, 2012). Being that this thesis is written within North America and with North American sensibilities, I have adopted the people-first language of "people/individuals with a disability" throughout this thesis.

The social model of disability arose as a reaction to the prevalent pathologizing of disability (Shakespeare & Watson, 2002; Barnes, 2009; Oliver, 2009; Martin, 2012), known as the medical model of disability. This medical model was reinforced by the World Health Organization's (WHO) early definition of disability as "any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being" (1980, p. 143) – a stark contrast to the UPIAS's definition of "disability." The social model of disability, taken to its dogmatic extremes gives rise to what Tom Shakespeare (2006; Shakespeare & Watson, 2002) views as a flaw in the model's current representation. To Shakespeare, what he refers to as the "strong" social model leads to the creation of a dichotomy, whereby an individual can only either support the social model of disability or support the medical model of disability – an individual not in support of the social model is, by default, in support of the medical model. Shakespeare recognizes that such dogmatic extremes are never really upheld, pointing out that, for example, "the issue of impairment was never really ignored" (2002, p. 6) by supporters of the social model. However, he sees the division between the public versus the private languages used by individuals in support of social models as creating the illusion that the social model of disability exists only in the dogmatic extreme. He takes contention with the fact that British supporters of the social model of disability use "strong" social model language in public, while discussing "aches and pains and urinary tract infections" (2002, p. 6) only in private. The contradiction between their public and private words/worlds ignores important aspects (i.e., diagnosis and medical intervention) of the holistic experience of individuals with disabilities. This flaw, as Shakespeare sees it, is present in both the UPIAS and Mad Studies.

In adhering to a rigid paradigmatic model (either social or medical), it is possible to lose sight of the multiple expressions of the experience of disability.

Anastasiou and Kauffman (2013) state the need for models of disability to incorporate subject-independent aspects (i.e., medical truth – a quadriplegic individual is unable to move their limbs) and subject-dependent aspects (i.e., an individual's experiences of that truth – how the person experiences quadriplegia, in part due to their social values) of disability in order to gain a holistic understanding of disability, thus breaking the rigid dichotomy of medical or social model.

In opposition to the creation of dichotomies between medical/social, oppressor/ oppressed, disabled/non-disabled, physical impairment/social disability, and stemming from the work of Merleau-Ponty (1962), Shakespeare and Watson argue for an "embodied ontology" (2002, p. 27) approach to disability. This call for an embodied ontology, which I see as a recognition of disability as simply an alternate way of being, is echoed in the World Health Organization's 2002 document *Towards a Common Language for Functioning, Disability and Health* (a modernized version of the 1980 document). In the document, the WHO outlines the definitions of both the medical model and the social model of disability before claiming:

> On their own, neither model is adequate, although both are partially valid. Disability is a complex phenomena that is both a problem at the level of a person's body, and a complex and primarily social phenomena…both medical and social responses are appropriate to the problems associated with disability. (2002, p. 9)

In acknowledging the importance of both the medical and the social models the WHO propose a new model of disability called the biopsychosocial model that "synthesizes what is true in the medical and social models, without making the mistake each makes in reducing the whole, complex notion of disability to one of its aspects" (2002, p. 9).

I situate this study in proximity to, and draw influence from, aspects of all the models outlined above – the UPAIS's (1976) early first-person phrasings of a social model of disability; Mad Studies' raison d'être in including the "words, experiences, and aspirations" (Menzies, LeFrançois, & Reaume, 2013, p. 13-14) of individuals with mental health issues; Shakespeare and Watson's (2002) call for an embodied ontology of disability as an alternate way of being; and the WHO's (2002) biopsychosocial models recognizing of the importance of the social and the medical in understanding the whole individual.

This research drew on the UPIAS's (1976) expression of the social model by acknowledging that social barriers are present outside of the participants' "impairments," and that by examining those external barriers, individuals with TS+ are able to begin undoing the internalized belief that all experiences associated with TS+ are somehow their fault. The study drew on Mad Studies (Menzies, LeFrançois, & Reaume, 2013) by allowing the experiences and words of the participants with TS+ to guide and shape the research (also a tenet of community-based research). The study drew on an embodied ontology (Shakespeare & Watson, 2002) by exploring what it means for TS+ to be simply another way of being in the world. The study drew on the WHO's (2002) biopsychosocial model by acknowledging that the social experiences of the participants both influenced and were influenced by their "impairments," (e.g. a student's presence in any given session may have been altered because they forgot to take their medication that day; because they were unable to sleep the night before and were tired; because a stressful situation outside the research caused anxiety, etc.). By pulling influence from these various socially inspired models of disability, this research study was able to find a unique approach, unhindered by the need to maintain a dogmatic adherence to any one model of disability, responding appropriately to the complex realities of participants' lived experiences.

My literature search for both TS+ and social models of disability uncovered several literature sources. In various ways, the literature uncovered influenced the design and process of this research study. It is of interest to note that a cursory exploration of the ERIC (Ovid) database and the PubMed database using both search terms "Tourette Syndrome" and "Social models of disability" did not uncover any literature. This is not to suggest that literature exploring the social models of TS+ does not exist, but it does suggest that such literature is possibly scarce further attesting to the need for research in this area.

First-person Experiences with TS+

My literature search on TS+ in relation to first-person experiences uncovered peer-reviewed academic articles, popular biographies, children's books, interviews, doctoral dissertations, and several videos expressing first-person experiences of TS+. While this literature did not include any community-based or theatre-based approaches, nor were there any explicit connections between any of the literature and social models of disability, the material did represent the first-person experiences of both youth and adults with TS+.

Beyond my personal experiences. In exploring the literature, I was able to locate TS+ outside of my own lived experiences – both my current lived adult experiences and the potentially fabricated memories of my youth experiences. In this way, I was able to better compare and contrast other youth and adult experiences, without running the risk of generalizing all experiences of TS+ based on my own lived/remembered experiences. Subsequently, I was able to better understand how my adult lived experiences related to the youth participants' experiences, and therefore I was able to better understand how my experiences related to those of the youth participants.

Brad Cohen's (2005) autobiography, *Front of the Class: How Tourette Syndrome Made Me the Teacher I Never Had* is one piece of literature that demonstrated adult experiences of TS+ outside of my own personal experiences. Cohen's autobiography highlights his experiences of TS+, from diagnosis as a youth, to dealing with stigmatization growing up, and finally gaining a sense of accomplishment and success in adulthood through his work as a teacher. These stages of TS+ development were mirrored in the experiences of Lance Turtle (Turtle & Robertson, 2008), who was a doctor in Liverpool, England with TS+. The overarching narrative of both Cohen's and Turtle's autobiographical stories was the use of negative experiences of TS+ to grow and strengthen oneself. Turtle highlights this narrative by stating, "people come in all sorts of shapes and sizes and with all kinds of bizarre characteristics. To be content you must accept the way you are, warts (or tics) and all" (Turtle & Robertson, 2008, p. 452). The aspects of Cohen's and Turtle's autobiographical experiences of TS+ mirrored my own experiences – being ostracized as a youth with TS+, and discriminated against as an adult with TS+ aided my successes as an adult. Like Cohen and Turtle, I have come to believe that my early experiences of TS+ have positively shaped me, and that my struggles with TS+ have provided me with strength. This is noted in a post to my personal TS+ blog dated to February 20th, 2015:

> TS+ is deeper than a disorder – it is a collection of shared experiences, which connect all people with TS+.
>
> These experiences of TS+ teach resilience and acceptance – they provide wisdom and courage to understand self and others.
>
> In short, it promotes humanity from the inside out. This is what makes me proud to have TS+. (Jeans, 2015)

In finding this parity between Cohen's, Turtle's and my own adult experiences of TS+, I was able to begin to understand the adult experiences of TS+ outside my own lived experiences.

Video representations of youth experiences of TS+. Much of the youth experience literature I discovered was in the form of video. Due to the performative nature of this research study, and my search for representations of first-person experiences of TS+, I found it valuable to search for videos of TS+. In watching these videos, I was able to compare the youth experiences of TS+ represented in the videos with my remembered experience of TS+ as a youth. In doing so, I was able to more accurately piece together my remembered experiences of TS+ as a youth and compare them to the more contemporary experiences of the youth with TS+ represented in the video as well as the youth participants in the study. For example, all the videos contain mentions of the experience of being socially ostracized to varying degrees (Golding & Bobula, n. d.; Luftspring & Moscovici, n. d.; Scott, 2006; Croswell, n. d.) – an experience that Cohen (2005) had also written about and which I remembered from my lived experience as a youth. In reconnecting to my lived childhood memories of TS+, I was able to build a stronger bond with the youth participants. The research was provided with a heightened sense of importance fuelled by the memory of my negative childhood experiences of TS+ – experiences potentially shared by the youth participants of the study.

While this personal connection with the uncovered videos provided heightened importance to the study, allowing the research to be fuelled by a personal connection also brought with it a potential danger – that of generalizing the experiences of TS+ (and therefore the research study) based on my own experiences. As with the adult experiences discussed above, the videos of youth with TS+ helped me to locate the youth experience of TS+ outside of myself – allowing me to reach beyond the emotional and psychological realms of my experiences. In locating both youth experiences and adult experiences of TS+ outside of myself, I was able to compare and contrast both experiences, with minimal imposition from my own experiences or from my potentially fabricated memories.

Many of the videos I reviewed, contained either an exploration of the schooling experiences or the social experiences of youths with TS+. As these videos were suitable for viewing by youth, as part of the research I watched the videos with my participants. The videos mirrored, in many ways, the experiences of the youth participants of this study, allowing them (and me) to gain knowledge of their experiences by witnessing similar experiences in others. An example of this mirroring of experiences occurred in the video entitled *Neil* (Croswell, n. d.). This short video is of a 14 year-old boy, who identifies himself as Neil, sitting in front of a camera describing his experience with TS+. In discussing TS+, Neil says: “You can also get bullied for it as well…like you can get made fun of for Tourettes. You may get called ‘retarded,’ or ‘special.’ And they may just be joking, but it can cut deep” (Croswell, n. d., 2:05). When I showed this video to the participants, this quote opened up a discussion on name-calling and friendship; all participants spoke of the emotional toll of being called names. Conversations such as this prompted by the videos became significant for generation of material for our inquiry.

A search of the YouTube video database provided several examples of first-person experiences of TS+, however due to the inability to authenticate the validity of sources, I did not include many of these videos in this review. The YouTube database search did uncover one video that fit within the parameters of my literature search. Sandi Scott's (2006) ITV broadcast *Teenage Tourettes Camp* provided an understanding of the experiences of TS+ from a first-person perspective of five British teenagers as they attended an American camp for youth with TS+. Throughout the research study, this video series was shared with youth participants in segments. The experiences represented in the documentary had such resonance with this study's participants that they would often recall moments of the video in subsequent research sessions. These recalled moments either generated dialogues relating experiences shown in the documentary with personal experiences, or were translated into moments of theatrical creation. The documentary's theme of social rejection followed by internalized loneliness resonated with the study's participants, leading to further sharing of experiences.

By introducing the documentary *Teenage Tourettes Camp* (Scott, 2006) into the sessions, this research study was able to uncover elements of the participants feelings toward TS+ including feelings of rejection that the youth participants were experiencing. These experiences, which linked with my own personal experiences as a youth with TS+, provided important points of reference for exploration throughout the research and also provided a narrative framework for the final script we developed.

The power of sharing experiences. Much of the first-person experience literature spoke to the importance of sharing experiences of TS+ with those unfamiliar with the disorder. The main rationale for sharing such experiences was to educate others, thereby reducing stigmatization. In some of the youth literature (Luftspring & Moscovici, n. d.; Buerhens, 1990; Peters, 2009; Bobula & Bobula, 2009; Golding & Bobula, n. d.), sharing experiences of TS+ with those unfamiliar with the disorder was seen to be accompanied by positive and transformational by-products – individuals with TS+ often realized that TS+ was more socially acceptable than previous thought, and they thereby (re)gained control of their own narrative. For example, in the @*Random* video entitled *Ethan* (Luftspring & Moscovici, n. d.), the subject of the video (Ethan) mentions the experience of delivering a presentation to his classmates, and how his classmates' newfound understanding of TS+ translated into increased social acceptance.

The narrative of students with TS+ presenting to their classes about the disorder and then experiencing furthered social acceptance is mirrored in several other videos and books, both in autobiographical and narrative forms. For example, the video *Spencer* (Golding & Bobula, n. d.) and the picture book, *Ticcing Thomas: The World's Fastest Arm Flapper* (Bobula & Bobula, 2009) (also based on Spencer, the subject of the video) both tell the story of a youth's fear of presenting about TS+ to his class. Like *Ethan*, Spencer's and Thomas' presentations were followed by acceptance from classmates. In *Ticcing Thomas: World's Fastest Arm Flapper* (Bobula & Bobula, 2009) the protagonist's presentation also provided strength to those around him. As Thomas shares in the book: "Some of my classmates even told me about some of their problems too" (Bobula & Bobula, 2009, p. 29).

The theme of a presentation leading to positive transformation was also found in the picture book *Tic Talk: Living with Tourette Syndrome: A 9-year-old boy's story in his own words* (Peters, 2009). This picture book starts with the protagonist's desperate struggle to hide his disorder from classmates, friends, and even teachers. After a presentation to his class about TS+, the protagonist realizes that, "it was just another day and nothing was different" (Peters, 209, p. 28), meaning that his fear that people would treat him differently once they discovered he had TS+ was unwarranted. The protagonist's mother even noticed that he "was having very few tics" (Peters, 2009, p. 29) after the presentation, which he attributed to not being "scared or nervous any more about people knowing [he] had TS" (Peters, 2009, p. 29-30). The desire to educate others served as the rationale for *Hi I'm Adam: A Child's Book about Tourette Syndrome* (Buerhens, 1990). Buerhens "wrote and illustrated [the] book because he want[ed] everyone to know he and other children with Tourette syndrome are not crazy" (backcover). He advises individuals with TS to "learn about what you have, then teach others about Tourette syndrome" (backcover).

By exploring biographical as well as fictitious literature themed around the transformational potential of sharing experiences of TS+, I felt assurance that an exploration of TS+ through theatre-based methods was not only justified, but also necessary. The need for youth with TS+ to share their experiences is also called for by Susan Conners, an educator with TS+ and founder and president of the New York chapter of the American organization, Tourette Syndrome Association (TSA). Conners' rationale for founding the New York chapter, and for her work with TSA was that the voices of youth with TS+ were not being heard in the classroom (Chamberlain, 2003). Through her in-school presentations with the TSA, Conners sought to educate those who know little to nothing about TS+, and also to empower those with TS+ who felt powerless (Chamberlain, 2003). As with the videos and picture books mentioned above, Conners provided this research with drive and purpose – this research held transformational potential for those with TS+.

Conclusion

This chapter began by reviewing literature (from the Tourette Canada website) that provided a defining framework for TS+, and examined the potentially negative impacts that stress can have on TS+. Next, an exploration of literature on socially influenced approaches to disability provided a framework for the research study, pointing to the need for this research to draw influence from various socially influenced models of disability in order to avoid limiting the research to dogmatic ideals. This chapter also reviewed literature that portrayed the first-person experiences of TS+ in both youth and adults. The literature showed the advantages that may be gained in sharing experiences of TS+, the potential benefits of increasing self-advocacy (as evidenced by the experiences of Brad Cohen, Lance Turtle, and myself), and potential pitfalls that stress may bring. In addition, the uncovered TS+ literature allowed for a deeper understanding of all participants (including myself) personal experiences of TS+ through having our experiences mirrored by others with TS+.

The theatre-based approach to community-based research employed for my study expands the academic literature available on the experiences of TS+. This research has the potential to contribute to understandings of first-person experiences of TS+, thereby building transformational potential of individuals with TS+, as well as the TS+ community in general.

CHAPTER 3

Methodology and Methods: A Theatre-Based Approach to Community-Based Research

This research study takes a theatre-based approach to community-based participatory research. True to the nature of *community-based research*, *participatory research*, and *theatre-based research*, the methods of this study allow the research to be emergent in its process, allowing for responsiveness to the context and situation.

This chapter begins with an overview of the transformative worldview lens that was used, and expresses the importance of transformation to the while project. Following this overview of transformative worldview, the chapter is arranged around two sections – the first section examines methodology and the second section examines method.

The first section explores the philosophical underpinnings of the methodology used in this research study. I begin with an outline of the transformative worldview that this study upholds. The chapter continues by examining community-based approaches to research, first by exploring the problematic issues involved in naming community-based approaches, and then by suggesting the similarities between the various community-based approaches – notably the notion of community-*based* versus community-*placed*. The methodology section of this chapter closes by exploring the background and tenets of popular theatre, and the strengths of popular theatre as a form of research.

The second section of this chapter discusses the methods used in this research study. I begin by laying out the study's objectives, provide a brief background to the intention behind this research study, and then outline the research design. Components of the research, such as participant recruitment, formulation of the research questions, data collection and analysis, teaching methodology, and evaluation design are discussed. The chapter concludes with a summary of the ethical considerations of the research study and finally comments on the limitations of the research.

Transformative worldview

The transformative worldview as a foundational perspective for conducting research grew in response to the "dominant paradigms and practices" (Mertens, 2013, p. 28) that were bred within the positivistic worldview (Brydon-Miller, Greenwood, & Maguire, 2003). The positivistic worldview values knowledge obtained through scientific method as the only form of "authentic" knowledge. In order to adhere to scientific method, knowledge must be observable, measureable, and repeatable (philosophybasics, n. d.). In contrast, the intentions of the transformative worldview are to give voice to issues of human rights and to serve marginalized populations (Deshler & Selener, 1991), while engaging with the issue of power at the various stages of research (Mertens, 2007). The transformative worldview does not adhere to the use of scientific methods to create "authentic" knowledge. In adhering to the intentions of a transformative paradigm, this study's intention was the provision of space where youth "placed-at-margins" could choose to use their voice(s) (both physical and metaphorical) and experience(s) to create, as Norris (2009) metaphorically puts it, "ripples" (p. 42) within their environment. Throughout the research, these ripples met with the ripples of other voice(s) and experience(s), which in turn generated the potential for transformation within the environment. This process of ripples meeting with, and thereby altering other ripples can also be seen as "feedback loops" (Diamond, 2007, p. 62). As Diamond describes, individuals are governed by patterns of behaviour that manifest themselves in the world as actions, or what Norris (2009) would refer to as "ripples" (p. 42). These actions, once placed in the world, draw reaction from other individuals. These reactions either reinforce the initial behaviour, or create an adaptation of that behaviour. This conversation of action/reaction, being played out from many perspectives, informs the transformation within the individual as well as community.

Transformation played a hugely important role in this study – both for youth participants and myself. In evaluating of the efficacy of this project, I looked to the transformative impact that the project had had on youth participants and myself. The dual intentions of this study were personal transformation for youth participants through co-created research, and societal transformation within the communities, which the youth inhabit. For youth participants, this research had the potential to build/strengthen self-advocacy skills, as well as build/strengthen confidence. Within the community, the potential for transformation was present in the community members' ability to re-see the youth participants in this more confident and self-advocating role. Through this research, the newfound confident actions of the youth participants (as witnessed during the performance) could bring about reaction from the audience that would either encourage them to adapt or reinforce the participants' confident actions.

The potential transformation emerged in various ways: firstly, the ripples of the voice(s) and experience(s) of each youth participant met the voice(s) and experience(s) of the other participants during the creation phase of the study; secondly, the ripples of the voice(s) and experience(s) of the youth met the experience(s) of the audience during the performance phase of the study; thirdly, the ripples of the voice(s) and experience(s) of each audience member met the ripples of the voice(s) and experience(s) of the other audience members during the discussion phases of the study; and lastly, the ripples of the voice(s) and experience(s) of the audience members met with the ripples of the voice(s) and experience(s) of the youth participants during the post-performance talk-back. A further ripple may be added here, which is the experience(s) of you, the reader, meeting with the voice(s) and experience(s) of the participants and I through the research represented in this written thesis. In this way, the scope of the transformational potential of the research may exist beyond the effects of the sessions with the youth and the final performance event.

Due to the polyvocal nature of this study, as described above, the topic being researched became complexified both on the stage and in the community, which in turn allowed for the emergence of new themes and patterns within the study and beyond (Norris, 2009; Diamond, 2007).

The ontology of a transformative worldview mandates that a research study be "explicit about the social, political, cultural, economic, ethnic, racial, gender, age, and *disability* values that define realities" (Mertens, 2007, p. 216, italics added for emphasis). In keeping with this ontology, this study defines the term "disability" in accordance with socially influenced approaches to disability (UPIAS, 1976; Shakespeare & Watson, 2002; WHO, 2002; Shakespeare, 2006; Rothman, 2010; Silvers, 2010; Menzies, LeFrançois, & Reaume, 2013; Anastasiou & Kauffman, 2013; ETTAD, n. d.), as opposed to medical models (WHO, 1980). That is to say, this research study views disability as a social and systemic construct, which arise out of the "access, stereotypes, [and] conceptions of 'normal'" (Rothman, 2010, p. 195) present in an environment as opposed to focusing on an individual's supposed "difference, deficit, or lack" (Rothman, 2010, p. 195) – without entirely abandoning the benefits that medical interventions might offer individuals.

Methodology

Community-based approaches to research. Community-based approaches to research, such as community-based research (CBR), participatory research (PR), and community-based participatory research (CBPR) are premised – quite simply – on community involvement on all facets of research. Community-based approaches to research strive towards acknowledging the interdependency within communities (Green, Daniel, & Novick, 2001) through collaboration with community members, researchers, and other invested parties (Strand, Cutforth, Stoecker, Marullo, & Donohue, 2003). Community-based partnerships are based on reciprocity, through which the research suits the interests of, and beneficially contributes to all partners involved (Israel, Schultz, Parker, & Becker, 1998; Green et al., 2001). Community-based approaches to research draw upon the expertise of individuals' experiences in order to engage with identified community issues, effect social change, and/or enhance understanding (Strand et al., 2003; Israel et al., 1998).

In completing the course work for this Masters of Education degree, I also completed course work for an embedded Community-Based Research and Evaluation (CBRE) graduate certificate. The course work for this graduate certificate focused on exploring community-based and participatory research models in practice as a means for identifying the tenets and theoretical underpinnings of the various models of community-based research. The coursework for his graduate certificate influenced the philosophical lens of this research study as well as the design and execution of this research study.

Naming community-based approaches to research. While there are many iterations and names for community-based approaches to research, which may suggest methodological difference, these community-based approaches are strongly connected through a set of shared underlying tenets.

As previously mentioned, I have defined this study as community-based participatory research (CBPR), which conflates the names community-based research (CBR) and participatory research (PR). To contrast CBR and PR, health research is often more inclined to use the term community-based research (Israel et al., 1998; Green et al., 2001), whereas the term participatory research tends to find greater use in education and initiatives in developing countries (Pain & Francis, 2003; Hall, 2005), although it should be noted that both health and educational research have utilized the term community-based participatory research (Israel, Schulz, Parker, & Becker, 2001; Sullivan & Siqueira, 2009).

While the three approaches (CBR, PR, CBPR) may be contrasted according to type of study, it is important to note that the similarities found in the values and principles that govern all three approaches far outweigh these differences. The similarities between CBR, PR, and CBPR begin with their philosophical grounding, drawn from Paulo Friere's seminal writing *Pedagogy of the Oppressed* (1970). The similar underlying values and principles of these approaches include (but are not limited to) community involvement, co-creation of knowledge, mutual benefit of researcher and community, and engagement with experiential expertise (Green et al., 2001; Hall, 2005; Flicker et al., 2007; Israel et al., 1998, 2001). After examining the differences and similarities between CBR, PR, and CBPR, I made a decision to define this study as CBPR. The *community-based* portion of the name highlights the study's connection to the larger Tourette Syndrome community, as opposed to connecting with the study's participants only. The *participatory* portion of the name highlights the co-creation aspect of the theatre process with youth – a process that closely mirrored Norris'

(2009) participatory theatre creation method of Playbuilding. The term community-based participatory research also acknowledges the interdisciplinary nature of my study drawing on health, education and the arts.

This research study adhered to participatory values and principles, acknowledging Cornwall and Jewkes' (1995) assertion that, "participatory research lies not in methods but in the attitudes of researchers, which in turn determines how, by, and for whom research is conceptualized and conducted" (p. 1667). Within this assertion, Cornwall and Jewkes allude to the pitfalls of adhering to participatory research methods as dogma, and instead create space for a researcher's *intentions* toward the values and principles of participatory research, without the necessity of achieving the dogmatic ideal. Cornwall and Jewkes (1995) allow for participatory research to focus on process along with the movement toward a product.

Community-based vs. community-placed in participatory research. Within community-based approaches to research, I felt it important to distinguish between the terms community-*based* research and community-*placed* research. Based on the work of Israel, et al. (1998), the University of Iowa's institutional review board defines community-*placed* research as "happening IN the community setting but is still researcher (academic) driven, community members are not active participants" (n. d., para. 3), whereas the university defines community-*based* research as "research WITH the community where the community members are participating to some degree in the research process" (n. d., para. 4).

According to the above definitions, community-*based* research allows research to be modelled by the community, thereby creating space for community experience(s) and expertise to influence and guide the research in both design and execution. In contrast, community-*placed* research forces the community to fit the research, thereby relegating community members to the role of "passive participants" (Horowitz, Robinson, & Seifer, 2009, p. 2635). Participatory research tends toward the inclusion of those otherwise passive participants. This inclusion may include (but is not limited to) community involvement in creating research questions, research methods, and data collection strategies. As the name suggests, participatory research relies on participation from the community and provides the participants with the "right to speak" (Hall, 1993, p. xvii).

In accordance with the definition of community-*based* research, this study involved the transformational potential of popular theatre (Prentki & Selman, 2000; Conrad, 2004, 2006), also known as *participatory* theatre (Butterwick, 2002; Ponzetti, Selman, Munro, Esmail, & Adams, 2009; Selman & Heather, 2015), within a community setting. The study relied on the co-creation of theatrical narrative(s) based on the experiences of youth participants. Due to the limitations of the master's degree program, a full adherence to the tenets of community-based approaches to research were challenging to uphold within this study. The issues surrounding the limitations of undertaking community-based research in a university degree program are discussed further in Chapter 5, the Reflections chapter.

Theatre as research. In the recent past, theatre has gained ground as a form of research in education, medicine and health care, and the social sciences. Barone and Eisner's (2006) work with arts-based educational research (ABER) is seen by some as a catalyst for theatre research in education, which has created space within education for theatre research initiatives such as *Are We There Yet?* (Ponzetti et al., 2009; Selman & Heather, 2015), "an award-winning, participatory, sexuality education theatre program for teens" (Selman &

Heather, 2015, p. xi) and *Boom*, a clown play exploring the issues of land mines in Croatia (Prentki & Selman, 2000; Salverson, 2001). In medicine and health care, initiatives such as *After the Crash* (exploring the care and treatment of individuals with traumatic brain injury) (Colantonio et al., 2008; Rossiter et al., 2008a, 2008b; Gray et al., 2011; Kontos et al., 2012, 2014) and The *Wit* Educational Initiative (examining end-of-life care through engagement with the Pulitzer Prize-winning play *Wit*) (Lorenz, Steckart, & Rosenfeld, 2004), are but a few that have demonstrated the potential of theatre as a tool for knowledge translation and dissemination. Within the social sciences, the connections between theatre and qualitative research have been well documented as a performative method (Conrad, 2004, 2006; Saldaña, 1998, 1999; Mienczakowski, 1995, 2009; Norris, 2009; Sawyer & Norris, 2013). Beck, Belliveau, Lea, and Wager (2011) point to Denzin's (1997) definition of "performance texts [as] a genre within ethnography" (p. 91), which is the "single, most powerful way for ethnography to recover yet interrogate the meanings of lived experience" (pp. 94-95), an assertion furthered by Mienczakowski's (2009) statement that the "purpose of ethnodrama or ethnotheatre/performance is to share the lived experience of our informants and influence change" (p. 327). Ethnodrama is "the reduction of field notes, interview transcripts, journal entries, and/or memoranda to what are salient, foreground issues" (Saldaña, 1999, p. 61). In ethnotheatre in scripted form, traditional theatre techniques are used to portray research participants as characters in a performance. Most often, actors are used to portray these characters on stage, however, Saldaña (1999) points out that at times research participants portray themselves or characters like themselves on stage. Ethnodrama can be a means of describing "phenomenon, in all its contradictions, messiness, and depth" (Mayan, 2009, p. 11), while also standing as a potential catalyst in the transformative process.

Popular theatre. Augusto Boal's work with *Theatre of the Oppressed* (1979) is one of several inspirations for contemporary popular theatre. Boal's *Theatre of the Oppressed* drew theatrical inspiration from Bertolt Brecht's *Epic Theatre* (Brecht, 1964), and social justice inspiration from the participatory education work of Boal's contemporary, Paulo Friere (1970). *Theatre of the Oppressed* was also born out of a rejection of, what Boal called, "Aristotle's coercive system of tragedy" (Boal, 1979, p. 36). Boal felt that the Aristotelian system of tragedy, which is built upon a drive toward audience catharsis, created passivity in audience members both theatrically and socially – a belief he shared with Brecht (1964). Boal's solution to this passivity was the creation of Forum Theatre, a theatre form in which audience members were able to stop the action of a play and place themselves into the role of the protagonist, thus becoming "spect-actors" (Boal's term for audience members who intervene in the performance) (Boal, 1979). The *Theatre of the Oppressed* emerged as a theatrical vehicle to provide cultural relevance, involve the experience and expertise of individuals within communities, and allow for the creation of personal knowledge through action (Boal, 1979). The inherent desire of popular theatre to transform "passive participants" (Horowitz et al., 2009, p. 2635) into active/contributing members is demonstrative of the resonance that occurs between popular theatre and community-based approaches to research.

While Boal's work is oft cited as one of the inspirations of contemporary popular theatre (Conrad, 2004, 2006; Ponzetti et al., 2009; Norris, 2009), the existence of popular theatre significantly pre-dates Boal's work with Theatre of the Oppressed. Joel Schechter (2003) points out that English popular theatre draws influence from the French "théâtre populaire" (p. 3). In 1758, French philosopher and writer Jean-Jacques Rousseau called for the creation of a People's Festival, a call that was taken up by one Rousseau's followers, Louis-Sebastien Mercier. Mercier looked to a people's theatre that would "mould the morals and manners of the citizens" (Schechter, 2003, p. 3) – a direction that would influence the eventual creation of "affordable and educational theatre for the masses" (Schechter, 2003, p. 3).

A 20th century extrapolation of Mercier's desire to "mould the morals and manners of the citizens" (Schechter, 2003, p. 3) can be found in the work of Bertolt Brecht, who explored ways of using theatre to enhance an audience's critical view of society (Brecht, 1964; Boal, 1979; Prentki & Selman, 2000) through the use of theatrical techniques such as the alienation effect[6]. The alienation effect allowed for analytical distance between the audience and the performance, thereby allowing audience members to view the underlying political undertones present in the script. In recent decades, the term popular theatre has emerged as a pragmatic umbrella encompassing several theatrical forms, including applied theatre (Prendergast & Saxton, 2009), participatory theatre (Conrad, 2004; 2006), and approaches that derive inspiration from the work of Boal (Diamond, 2007; Mienczawkowski, 1995, 2009; Norris, 2009; Saldaña, 1998, 1999; Sawyer & Norris, 2013).

Popular theatre in Canada. The roots of popular theatre in Canada can be traced back to the work of Ross Kidd, an adult educator and popular theatre practitioner who travelled the world to work with and learn from other popular theatre practitioners (Kidd, 1978; 1979; 1984; 1985). In the 1970's, Kidd's influence on the roots of Canadian popular theatre was demonstrated in the creation of theatre that was "for, with, and by the people" (David Barnet, personal communication, February 4, 2016; Kidd, 1978, 1979, 1984, 1985). According to

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[6] The Alienation Effect (or verfremdungseffekt) was Brecht's response to what he saw as the artifice of theatre. The alienation effect sought to emotionally distance the audience from the performance by purposefully exposing the theatrical pretenses of the performance, thereby allowing the audience to view the performance with a critical eye (Brecht, 1964).

Prentki and Selman (2000), popular theatre “came to Canada” (p. 73), in 1978 when Kidd, who had been using theatre as a “development tool” (p. 73) in Africa, came back to Canada. In the fall of 1978, social and political theatre practitioners from across Canada, along with Ross Kidd, gathered in Newfoundland to “debate about the work…[and] its intentions” (Prentki & Selman, 2000, p. 73). While political and social theatre was already being created in Canada at this point (e.g., Theatre Passe Muraille; Mummer’s Troupe; Catalyst Theatre), mostly referred to as collective creation, Kidd was credited with the introduction of the term “Popular Theatre” into Canadian political and social theatre (Prentki & Selman, 2000).

In the early 1970s, Theatre Passe Muraille (Theatre “beyond walls”) was founded in Toronto, Ontario and used collective creation (Prentki & Selman, 2000), a “technique of devising a play as a group, with or without the aid of playwright or dramaturge” (The Canadian Encyclopedia, n. d., para. 1), to build their performances. This form of theatrical creation was commonly used prior to Theatre Passe Muraille, however, this theatre company truly embraced the technique as a means of creating theatre with communities (Canadian Theatre Encyclopedia – Theatre Passe Muraille, n. d.). Perhaps the most influential of Theatre Passe Muraille’s collective creation plays was 1972’s *The Farm Show* – a play so influential in Canadian theatre history that a second play called *The Drawer Boy* (Healey, 1999) was written about the process of creating *The Farm Show*.

At the time that Theatre Passe Muraille was using collective creation in Ontario, the technique was also being used by Mummers Troupe in Newfoundland and Labrador (Prentki & Selman, 2000; Heritage Newfoundland and Labrador, n. d.). The mandate of Mummers Troupe, founded in 1972 by Chris Brookes and Lynn Lunde, also embraced a collective creation approach to “restore a sense of dignity in the idea of being Newfoundlander, [and] to speak to and for the people of different Newfoundland and Labrador communities" (Heritage Newfoundland & Labrador, n. d., para. 4). Although Mummers Troupe disbanded in 1982, the ripples of their collective creation work continues in Newfoundland and Labrador to this day. One of the Mummer Troupe's core members, Donna Butt, went on to found Rising Tide Theatre in 1978 – a company that "began by writing and producing political plays that addressed controversial issues of Newfoundland and Labrador" (Rising Tide Theatre, n. d., para. 1). Today, as a part of their Summer in the Bight theatre festival located in Trinity, Newfoundland, Rising Tide Theatre continues to write and adapt plays that address political and social issues of relevance to the people of Newfoundland and Labrador.

Deriving direction from the collective creation approaches of Theatre Passe Muraille and the Mummer's Troupe, and influenced by the Theatre in Education (TIE) work practiced in the UK, and the seminal teaching of Dorothy Heathcote (David Barnet, personal communication, February 4, 2016), David Barnet started Catalyst Theatre in Edmonton, Alberta in 1977 with the mandate to "promote and practise the use of theatre for public education and as a catalyst for social change" (Canadian Theatre Encyclopedia – Catalyst Theatre, n. d., para. 1). In 1979, Catalyst Theatre hired Jan Selman as the company's Artistic Director – a position she held until 1985 (Canadian Theatre Encyclopedia – Catalyst Theatre, n. d.). In 1996, Catalyst Theatre, under the artistic direction of Jonathan Christenson, moved in the new direction of "creating original Canadian work that explores new possibilities for the theatrical art form" (Canadian Theatre Encyclopedia – Catalyst Theatre, n. d., para. 4). While the revised mandate marked a shift in the direction of Catalyst Theatre, founder David Barnet, as well as former Artistic Director Jan Selman, have continued the creation of popular theatre in Edmonton, AB, and across Canada.

Popular theatre as participatory research. While popular theatre dwells in the arena of performative arts, the social underpinnings of this movement are consistent with participatory research. According to Conrad (2004), popular theatre as participatory research "involves shared ownership of the research process and community-based analysis of issues, all with an orientation toward community action" (p. 15). This is echoed by Prentki and Selman's (2000) definition of popular theatre as "deeply involv[ing] specific communities in identifying issues of concern, analyzing current conditions and causes of a situation, identifying points of change, and analyzing how change could happen and/or contributing to the actions implied" (p. 8). Both definitions allude to popular theatre emerging from community, promoting community ownership over knowledge, and tending toward action within the community. These tenets of popular theatre are mirrored in participatory research, which tends toward creating "relationships between academic and community partners" (Wallerstein & Duran, 2006, p. 312), building "on local knowledge and strengths" (Flicker, 2008, p. 70), and "focus[ing] on 'knowledge for action'" (Cornwall & Jewkes, 1995, p. 1667). To further link popular theatre and participatory research, Conrad (2004) points to the tradition of participatory research in using artistic methods such as "photography, radio, poetry, music, myths, drawing, sculpture, puppets, and popular theatre" (p. 15).

In referring to my research study as CBPR, I implicitly draw on the connection between participatory research and popular theatre. I draw influence for my script writing from ethnodrama (Saldaña, 1998; Mienczakowski, 2009), which seeks to present experience through a "consensually informed…scripting process" (Mienczakowski, 2009, p. 323), while my transformative worldview draws influence from David Diamond's (2007) *Theatre for Living* (which is influenced by Boal's *Theatre of the Oppressed*). Diamond's *Theatre for*

Living honours the interconnectivity present between individuals within a community, and as such, seeks to uncover the cause and effect of individual actions within community (Diamond, 2007). My research methods bring together the "consensually informed" (Mienczakowski, 2009, p. 323) scripting process of ethnodrama with the perspective of interconnectivity present in *Theatre for Living* (Diamond, 2007) to explore the stigma of disability as framed by socially influenced approaches to disability.

Methods

Study objective. The general aim of this research study was to create awareness and understanding about the first-person experiences of TS+. A theatre-based approach (i.e., popular theatre) was chosen for its ability to create space for youth with TS+ to share their experiences with a mixed audience of individuals who either have an understanding of TS+ or have minimal (or no) understanding of TS+. The study allowed participants to use the space created during a series of workshop sessions to build self-advocacy skills and strategies and/or to improve their self-confidence.

Research questions. To reiterate, this study sought to examine the overarching research question: *What are the experiences of TS+ for youth aged 14-15?* This overarching question suggested the sub-questions: *What experiences impact youth with TS+? What are the social ramifications of these experiences? How do these experiences affect the youths' social status and educational experiences?* Through the process of creating a theatre performance, video interviews, presentation of the performance for an audience, and an audience talkback session, data that contributed to answering these questions was generated and disseminated. Further discussion of the findings related to these research questions can be found in Chapter 5.

Background of the study. The intent of the following section of the thesis is to explain the research design of this study to elicit first person experiences of TS+ with youth participants. This research study understands that well-intentioned adults (i.e., teachers, medical professionals, friends, and possibly even family members) may inadvertently create narrative(s) of youth with TS+ without input from the youth. This can lead youth with TS+ to identify with externally created narratives, as opposed to exploring their personal lived experiences. Externally created narratives, linked without self-exploration of personal experience may lead to a lack of ownership over personal experiences, which in turn may create difficulties in distinguishing between well-intentioned (i.e., teachers, medical professionals, friends, and family) and ill-intentioned (i.e., bullies) individuals, as both may limit the youths' ability to build personal identity. This inability to distinguish between well-intentioned and ill-intentioned individuals may lead to feelings of isolation. Through theatre, youth participants in this study engaged with themes of self-constructed and socially constructed identification. The research study hoped to offer participants "new ways of seeing, constructing and responding to the world around [them]" (Altruz, 2013, p. 45).

Research design. The research design of this study was influenced by the tenets of community-based approaches to research, framed by socially influenced approaches to disability, and examined through the lens of a transformative worldview.

Participants. Within qualitative research, sampling is meant to identify individuals who have experiences matching the focus of the study (Mayan, 2009). Due to the study's examination of lived experiences of youth with TS+, a random sampling of participants was not sought, but rather participants were chosen if they met the following criteria: must have lived experience with TS+; must be between 13-18 years of age; must live within an area accessible to the University of Alberta campus (or be willing to attend sessions on University of Alberta campus for the Saturday sessions); must willingly assent to participate in the study and have parents or guardians consent to their participation in the study (if under the age of 18). Prior experience with theatre was not a part of the recruitment criteria. The original research design sought to recruit a sample size of 4-8 youth with TS+ between the ages of 13-18.

Participant recruitment. In partnership with the Edmonton chapter of Tourette Canada, I was able to connect with adults and youth with TS+ who took an interest in participating in the study. Recruitment notices were sent through emails, chapter newsletters, and posted on the Tourette Canada Edmonton chapter's website. The partnership with the Edmonton chapter of Tourette Canada also led to connections with other Edmonton-based organizations that serve youth with TS+, such as Adaptabilities. Through these services, I was better able to connect with potential participants during the study's recruitment process. One participant, who took a leadership role during the sessions, was recruited at a Tourette Syndrome Teen Night that I was invited to attend. This Tourette Syndrome Teen Night was organized by Adaptabilities.

The age range of participants was chosen to account for the peak severity of Tourette Syndrome related tics[7]. Four participants with TS+ between the ages of 14-15 were recruited to the research study – a fifth participant who began with the study withdrew early in the study. The study was adapted to engage this limited age range. In addition to the youth participants, approximately 60-70 audience members from the University and Tourette Syndrome communities attended a sharing-celebration.

Data collection and analysis. In the initial design for this research study, participatory sessions (including theatre creation, video interviews and the performance) with the youth were scheduled to occur over the span of 14 sessions – starting on September 13th, 2014 and ending on January 31st, 2015. A final sharing-celebration was set to occur on February 7th, 2015. In December 2014 a decision was made with agreement from youth and their parents to extend the study for another six sessions. Due to this extension of time period, as well as the need to address various other emergent ethical considerations, an amendment to the study's initial ethics review was submitted to the University of Alberta Research Ethics Office in December 2014, and was subsequently approved on January 7th, 2015. The study was ultimately undertaken over a total span of 20 sessions. These sessions culminated in a sharing-celebration where youth performed a piece of research-based popular theatre that had been created for an invited audience.

As this study used theatre-based research (i.e., popular theatre) as the mode of data collection and analysis, the term "data" itself became problematized within the research. In

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[7] Much of the TS literature points to the peak severity of tics occurring between the ages of 14-18 (Turtle & Robertson, 2008; Tourette Canada, n. d.; Packer, n. d.; Grace & Russell, 2005; Conelea et al., 2010; Cohen & Wysocky, 2005; Chamberlain, 2003). 80% of individuals with TS will experience a sharp decline in TS related tics by their late teens (Tourette Canada, n. d.).

quantitative/positivistic research studies, data is generalizable, reproducible, and involves a sense of rigour based on “internal validity, external validity, reliability, and objectivity” (Lincoln & Guba, 1988, p. 3); however the material generated in a theatre-based research study is individualized and experiential, phenomenological, and has an implied sense of rigour, which Norris (2008) refers to as “internal rigour” (p. 230). In this research study, “data” took the form of participants’ personal experiential narratives (whether in spoken, written, video-graphic, and pictographic form), participant created scenes (the written script which was informed by the improvisationally created scenes of the participants), and the audience’s questions, comments, and feedback collected during the discussion/talkback during and after the performance. These pieces of “data” followed Lincoln and Guba’s (1986) “parallel criteria for trustworthiness” (p. 76) for qualitative research (which Lincoln and Guba called Naturalistic Inquiry). Their “parallel criteria for trustworthiness” (p. 76) included credibility (there is truth in the findings), transferability[8] (the findings are applicable to other contexts), dependability (the findings are able to be repeated), and confirmability (the findings are shaped by participants and not solely based on researcher bias) (Lincoln & Guba, 1985, 1986).

In this research study, the participants’ experiential narratives came from their own personal realities (credibility); the underlying emergent issues, such as bullying, that were present in our discussions and the final performance, could be mirrored in other educational and disability contexts (transferability); the experiences of TS+ that were shared by individual participants within the research study were also shared by other members of the group (myself included), as well as mirrored in video representations of TS+ we watched

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[8] It is of importance to note that Lincoln and Guba (1985, 1986, 1988) draw a distinction between “transferability” – applying the findings to *specific* other contexts – and “generalizability” – applying the findings to *all* other contexts.

during early sessions of the study (dependability); and attention was paid to removing my personal biases from the "data" shared by participants (confirmability).

Further data collected during this study were videoed interviews of participants, which were interspersed with photographs and shown during the final performance. In addition, the final performance itself was video recorded and a copy of that video (with consent from youth and parents) was given to Tourette Canada to use in future educational initiatives.

Teaching and theatre methodology. While this educational research study was initially designed to follow three distinct phases (examination of video representations of TS+; exploration of emergent themes and patterns through the creation and rehearsal of a forum theatre play; performance of the forum theatre piece) which followed a pre-determined schedule, in keeping with the tenets of community-based research, the actual sessions advanced, not according to a pre-determined schedule, but instead followed the organic patterns and structures that emerged through participant engagement from one session to the next. This attention to process represented a conscious effort on my part to alleviate tensions between the "curriculum-as-plan and curriculum-as-lived-experiences" (Aoki, 2005, p. 159), which arose between the initial research design and the lived-experience of the actual research study sessions.

While the intent to create a piece of theatre based on the first-person experiences of youth with TS+ helped to anchor the directional flow of the study, the participants' engagement in each session heavily influenced the methods that were used during each session. For example, during one session only one of the four participants attended. As the only one in attendance that day, the solo participant did not wish to work on scene creation or other performance-based activities, so during that session we designed and began creating a brick wall to serve as a set for the performance. The engagement level of participants in this research study varied from session to session depending their desires to involve themselves in the activities during that session[9]. The organic and emergent data that arose in the research study, as well as the varying degrees of youth engagement, appropriately influenced the pedagogical direction of the study and continually shifted the pedagogical atmosphere from session to session.

Throughout this study, I used various theatrical techniques and activities. During the initial sessions, I introduced some theatre games and activities to build group dynamics. Some of these games, such as a group favourite called *Ninja*, continued throughout all sessions. In addition to theatre games, I incorporated improvisational activities into the sessions to create frameworks for scenarios. One such improvisation provided a foundation for the final performance. During improvisational activities, tableaux, or frozen-images, were often used in attempts to create beginnings, middles, and endings of scenes. Three tableaux moments were also incorporated into the final performance as a way of demonstrating to the audience the pre-existing bullying of the protagonist. The use of tableaux was incorporated for several reasons: to allow audience members an opportunity to witness the bullied protagonist (and perhaps even the bullies!); the tableaux provided the audience with contextual background about the characters and the situation, providing an immediate understanding of the characters' social status. The final two or three sessions involved performance rehearsal techniques such as photographing frozen moments to help participants

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[9] At times, the associated disorders experienced by participants as well as medications connected to these disorders (or forgetting to take medications) led to participants not wishing to involve themselves in the session's activities due to tiredness, irritability, lack of focus, anxiety, or a number of other reasons.

understand the stage pictures being created, or doing quick-line runs to help participants remember their lines.

Evaluation design. The evaluation design of this research study drew inspiration from evaluation models used in other theatre-based research initiatives (Gray, Ivonoffski, & Sinding, 2002; Shapiro & Hunt, 2003; Lorenz, Steckart, & Rosenfeld, 2004). I wanted to evaluate theatre's ability to demonstrate first-person experiences of TS+, as well as the participants' transformation during the process of the research study. To these ends, evaluative data were gathered from audience members through discussions during the performance and at the talkback following the performance and through informal discussion with audience members directly following the sharing-celebration. Data collected throughout the study from youth, including video and audio recordings, as well as comments made by youth during the talkback were also used as data for evaluation. Evaluative data was gathered from youth participants through video recorded interviews conducted during the last few sessions of the study.

Ethical considerations. This study received full ethics approval from the University of Alberta's Research Ethics Office on September 3rd, 2014. A subsequent amended ethics submission was approved on January 7th, 2015.

Informed consent. Youth participants of this research study were required to provide parental consent as well as personal assent. In providing assent, participants understood that: experiences shared throughout the research study could be used as data; they could withdraw from the research study at any time; if withdrawing, they could request that any data they contributed not be used as part of the research study (this would be accommodated to the extent that it did not impact the integrity of other contributed data); participants or their parent could request any experiences shared during the sessions not be used as data; the data collected during the research study would remain confidential; and they could choose not to participate in any of the activities undertaken during the study. At the beginning of the study, participants were informed to share only as much information as they felt comfortable sharing. This was echoed throughout the study, and reinforced prior to the post-performance talkback during the sharing-celebration.

Audience consent. Prior to the sharing-celebration talkback, audience members were reminded that participation in the talkback would imply consent; by offering a question or a comment they were consenting to allow their question or comment to be used as data. Prior to the talkback, audience members were advised to share only as much information as they felt comfortable sharing.

Risks. There was minimal risk involved in participating in this research study. During the early sessions, the youth and I watched video representations of TS+ as a way of contextualizing social or school based issues encountered by others with TS+. I did anticipate that some of the videos, as they dealt with situations that may have been closely related to the experiences of the participants, might have led to stress, anxiety, and discomfort. Participants were also invited to share stories of their personal experiences with TS+, which I thought might also have led to stress, anxiety, and discomfort. The potential for stress, anxiety, and discomfort was increased due to the associated disorders that some of the participants with TS+ experienced, which included anxiety disorder.

While there were minimal risks associated with the research, precautions were taken to ensure the safety of the participants. To minimize the risks associated with the study, I ensured that the environment in which the sessions occurred was safe and inclusive. Creating this safe and inclusive environment included building trust amongst the group members, while also reminding participants to only share information that they were comfortable sharing with others. If participants became stressed or anxious during a session, they were able to leave the space. A Tourette Syndrome community volunteer was always present in the space and therefore was able to sit with, talk with, or listen to participants who needed to leave the room due to stress or anxiety.

Early in the study, participants shared their experiences with associated disorders with the group. Issues such as how these disorders manifested, how they were triggered, and, if they arose during our sessions, how a participant would like them dealt with were discussed. During the study, there were some incidents that arose, for example some participants had anxiety attacks during early sessions. These situations were approached with care and consideration for the safety and wellbeing of the participants.

While it is potentially stressful to perform on stage, the theatrical form itself offered participants the ability to distance themselves from their characters. In this way, participants could safely examine the experience of their character from a distance. This distance allowed participants to analyze certain characteristics without internalizing the issues and emotions of that character. This further minimized the impacts of stress and anxiety.

There was also minimal risk that the issues presented in the performance would create anxiety and stress in the audience. Audience members were told that the performance was being recorded and that anything discussed during the talkback would be considered as data for the research study. To that end, audience members were advised to share only as much as they felt comfortable sharing. Audience members were permitted to leave the space at any time and re-enter again when ready. If audience members were impacted by the performance and wished to talk about it further, members from Tourette Canada Edmonton chapter were available to speak with them. In addition, phone numbers for the Tourette Canada Edmonton chapter were readily available as well as other emergency and help phone numbers, such as Capitol Health, LINK, and the Help Line.

Benefits. The benefits of this research study far outweighed the risks. The benefits for participants included the potential to increase self-confidence, build and/or improve self-advocacy skills, build self-confidence, and/or improve upon socialization strategies. In addition, the potential was present for participants to learn more about TS+, and to build upon their knowledge of their experiences of TS+. The benefits for audience members was the potential to build upon emerging or existing understandings of TS+, as well as the potential to confront biases, assumptions, and/or misunderstandings about the experience of TS+.

Limitations. According to multiple literature sources, the peak severity of TS+ related tics occur during late teenage years and early 20s (Turtle & Robertson, 2008; Tourette Canada, n. d.; Packer, n. d.; Grace & Russell, 2005; Conelea et al., 2010; Cohen & Wysocky, 2005; Chamberlain, 2003). Depending on the literature, the age of the peak severity of tics can range from 11-20 years old. While the literature did inform the age range, the ultimate decision to set the age range as 13-18 was made to allow the research to reflect TS+ throughout the high school years.

Although this research was initially designed to recruit participants between the ages of 13-18, no participants over the age of 15 were recruited – the age range of the four participants was 14-15. Therefore, while the study aimed to examine the high school experience of individuals with TS+, the narrow age range did not provide the research study with any data of the experience of older teens. This narrowed age range limited the exploration of the experience of TS+ to grade nine. The research was further limited due to the small number of youth (4) who participated in the study. The limited number of youth participants impacted the studies ability to get an extensive understanding of the experience of TS+ within the youth population.

The Script Creation. In his book *Games for Actors and Non-Actors* (1992) Augusto Boal points out that theatre games are a "physical reflection of oneself" (p. 60), a notion echoed by Diamond's assertion that theatre games can "unlock access to the issues that the group wants to investigate" (2007, p. 91). Throughout the process of this research study, I attempted to interject theatre games as a part of the methodology. The participants approached the theatre games with varying degrees of engagement. In the moments that the group did engage in these theatre games, the resulting images created and stories told revolved around power-struggles (often involving some sort of bullying) and group status. These issues of power-struggles and status had not been in the forefront of my mind when I had entered the research study, however these stories arose from the theatre games (which may also have been influenced by the TS+ videos watched during early sessions) – from the collective consciousness of the group, and therefore they needed to be central to the story that we were going to tell.

The next chapter contains the final script created with the youth for the sharing celebration. It was created through group activities and theatre games and as such is a representation of the group's collective experiences.

CHAPTER 4

Ditch(ed): A Performance Script Devised with Youth About their Experiences with Tourette Syndrome Plus

Background

The script for this research study was devised over a period of twenty 3-hour sessions between September 2014 and March 2015. The script was a co-creation between myself and four youth participants with TS+. The script creation process was initiated by providing youth participants with loosely structured story frameworks, upon which they would create improvised scenes. These frameworks were grounded in character analysis and the exploration of power dynamics between characters. For example, during one of the script creation sessions, I suggested to one participant a scenario in which his character was caught in the middle between two friends – torn between being popular on one hand and maintaining a friendship on the other. This scenario eventually became the basis for the creation of the Billy character. After several improvisational iterations, scenes such as the one described above were filmed. I wrote a script based on these improvised scenes. In the final script some of the characters' lines remained the same from the improvised versions, some dialogue was altered, and other lines were added to build dynamic characterizations, clarify story, and build on conflicts that were implied during improvisations. The script was structured to present a problem or an issue during or at the end of each scene. Solutions to these problems or issues were never offered within the script, but rather the problems and issues were intended to provoke audience discussion.

Interspersed throughout the live performance were four video segments, each video, approximately two minutes long, was projected on a screen at the back of the stage. These videos contained edited clips taken from interviews with all four participants. These edited clips highlighted the various themes present in the script. The video segments were titled: The Process, The Bully, Friendship and Fitting In, and Moving Forward.

The live performance also included four discussion sections with the audience that accompanied onstage scenarios. Discussions were based on a problem or issue presented on stage. During these discussions, the action of the play was stopped, and I in the role of the Joker (Boal, 1979; Conrad, 2004; Diamond, 2007), reiterated the moment from the performance that had just occurred, and then provided provocation for audience discussion in the form of a question. The discussion prompts were projected on screen. The audience discussions were facilitated through a modified classroom technique called "turn-and-talk" (theteachertoolkit, n. d.) More about the "turn-and-talk" method can be found in the "Reflection" chapter that follows. The discussions that occurred provided audience members the potential to build on their understandings of the scenarios and issues present in the script.

Characters

The dialogue of this script is broken into two sections – the video interviews and the performance. To protect the identity of the youth participants, the video interview sections of the script use only the participants' initials to denote the speakers. During the fictitious elements of the script, characters' names are used. A character list is provided follows, which also connects youth participants in the video with the role they played during the performance.

Character Breakdown *(in order of appearance):*

Thomas: A high school student with Tourette Syndrome. According to his accounts, he is often bullied at school.

Amber: A high school student who is seen by other students as very popular. Amber has a desire to be accepted by Tiffany, Nicholas, and Trent, who Amber sees as the most popular students in school.

Tiffany & Nicholas: Two high school students who Amber sees as the most popular students in school. Tiffany and Nicholas appear onstage during the play as non-speaking, masked characters.

Lily: A high school student and friend of Amber. She is torn between maintaining her friendship with Amber, and being accepting of others.

Billy: A high school student and a sometimes friend of Thomas. Like Lily, Billy often finds himself torn between his friendship with Thomas and his desire to hang-out with the "popular" teenagers.

Video Cast List *(in order of appearance)*:

AC: Youth Participant – Plays the role of **Amber**

Alan: Researcher

Lisa: Research Assistant/Tourette Syndrome Community Volunteer

KO: Youth Participant – Plays the roles of **Lily** and **Tiffany**

MC: Youth Participant – Plays the role of **Thomas**

CK: Youth Participant – Plays the roles of **Billy** and **Nicholas**

Setting

The setting of this play occurs in two locations – Maplewood High School and the local mall. The play opens with a series of tableaux that take place in the hallway of Maplewood High School. Scenes 1-3 take place by “the wall” outside Maplewood High School. Scenes 4a, and 4b take place in the local mall. For scene 5, the setting shifts back to “the wall” outside of Maplewood High School.

During the performance, the various settings are highlighted via projections on a screen at the back of the stage. During scenes 1-3 and 5, which all occur at “the wall,” a brick wall with the school name, “Maplewood High School,” was projected on the screen. During scenes 4a and 4b two different pictures of the inside of a mall were used. Two pictures were used to represent that **Thomas** and **Billy** were hanging out in a different part of the mall than **Amber** and **Lily**.

In addition to highlighting the setting, the screen was also used to display text messages that were sent between characters. At the moments in the script where a text message is sent between characters, that text message was projected on the screen.

Plot Synopsis

This play focuses on the concepts of identity and self-perception. Thomas, a high school student with Tourette Syndrome, feels that the first thing anybody notices about him are his tics. His social reality is framed by characters such as Amber, who are popular with other students, but who bully Thomas, or by characters such as Billy, Thomas’ best friend, who is keen to hang-out with Thomas until something or somebody more interesting draws his attention elsewhere.

As the play begins, Thomas has been bullied and wants simply to be left alone. However, finding the opportunity to be alone proves difficult. He is first bothered by the appearance of Amber, who mocks and bullies Thomas. Next Thomas' solitude is interrupted by Billy, his best friend who insists that Thomas hang-out with him at the mall.

While at the mall, Billy receives a text inviting him to see a movie with Amber and Lily, but he is told that Thomas is not invited. Billy decides to ditch Thomas, and joins Amber and Lily in the food court. In the plot's climax, Thomas finds Billy, Amber, and Lily, in the food court, as they are about to go to the movie. Thomas is finally invited to join the group and attend the movie – an invitation he refuses.

Prologue

(As the audience settles into their seats, the video projection on the screen begins a slow dissolve from the TITLE SCREEN proclaiming, "Touretteton Productions Presents – DITCH(ed)" into a quote titled "TS PRIDE.")

> **TS Pride**
>
> **TS is deeper than a disorder – it is a collection of shared experiences, which connect all people with TS.**
> **These experiences of TS teach resilience and acceptance – it provides wisdom and courage to understand self and others.**
> **It short, it promotes humanity from the inside out. That is what makes me proud to have TS. – Alan Jeans**

(From this screen, another slow dissolve occurs to a poem written by one of the participants. The poem is entitled "Pain.")

Pain

You must hurt

In order to know

Fall

In order to grow

Lose

In order to gain

Because life's greatest challenges

Are learned through pain

– Krista

Video # 1 – The Process

(Ambient music is heard over a blank screen. Over the ambient music the following introductory clips are presented.)

AC

(A still camera mid-range shot of AC, a teenage girl, seated on a stool. Behind her is a mirror. In the shot we see her side profile in reflection. The girl claps her hands together as though they were a movie clap-board) Action!

(Next is a black screen with the words "TOURETTETON PRODUCTIONS." Under this black screen voices are heard.)

Alan

(off camera) Are we running?

Lisa

(off camera) Yup! We're rolling!

Alan

(off camera) We're rolling!

(Black screen gives way to a still camera mid-range shot of KO, a teenage girl, seated in the same location as AC was seated in the previous shot – in front of a mirror. In the mirror we see her side profile. KO looks at the person seated behind the camera with a surprised look on her face.)

KO

Oh wait! I just…ok let's go!

(Another black screen with the words "In collaboration with" written across it. The screen changes to the ***Tourette Canada*** *logo followed by the* ***University of Alberta*** *logo. Under the second logo voices are heard.)*

Alan

(off camera) Ok, are you ready?

(Black screen gives way to a still camera mid-range shot of MC, a teenage boy. He is seated in the same location as AC and KO were seated in previous shots – in front of a mirror. In the mirror we see MC's side profile reflected.)

MC

Let me get the jitters out. *(Shakes his whole body.)*

(Another black screen with the word PRESENTS appearing. Under the black screen voices are heard.)

Alan

(off camera) What would you say to that person?

(Black screen gives way to a still camera mid-range shot of CK, a teenage boy. He is seated in the same location that MC, AC and KO were seated in the previous shots – in front of a

mirror. In the mirror we see CK's side profile reflected. In all the interview segments throughout all videos, the participants are seated in the same location.)

CK

Ummm…well…I guess…I don't know what to say…ummm…

(Another black screen with the words DITCH(ed) appearing. The ambient music fades out.)

Alan

(off camera) To people who know nothing about Tourette Syndrome, what would you want to tell them?

CK

I wouldn't call it a mental disability, it's not something that really stops you from learning or anything.

(Screen fades out on CK and fades in on KO.)

KO

It's not fun…to have. It's extremely hard to control. You have to, like, get taught to, like, calm down and breathe and it's quite difficult.

(Screen fades out on KO and fades in on AC.)

AC

People still give me, like, a lot of anxiety and stress.

(Screen fades out on AC and fades in on KO.)

KO

…it's stressful too.

(Screen fades out on KO and fades in on AC.)

Alan

(off camera, to AC) When you have anxiety, what strategies do you use?

AC

Usually I…I have this strategy, it's, like, called grounding. Ahh…grounding is, like, say, like, you're in a stressful situation and…ummm…cause it [the strategy] is teaching you not to run away from it [the stressful situation], cause that's what a lot of strategies do. It's teaching you to just get back into the green zone.

(Screen fades out on AC and fades in on KO.)

KO

Ummm…It's kinda like…like…I think it kinda has to do with my emotions. So, it's kinda like Elsa, when she's, like, in Frozen, when she gets, like, stressed out and whatever, her powers go everywhere and she just can't control them…*(smiling)* like the song "Let it Go!"

(laughter on camera and behind the camera)

(Screen fades out on KO and fades in on MC.)

MC

I thought that people with Tourette Syndrome just, like, couldn't handle…or couldn't control any of their actions. But now I understand that certain people…different people have different…ummm…symptoms from Tourette Syndrome.

(Camera fades out on MC and fades in on CK.)

Alan

(off camera) Any last words…you want to say…

CK

(ambient music comes in underneath) It'll be fun…to do the play! That's it!

(Screen goes to black.)

End of Video # 1

(Ambient music continues to play. During this period of ambient music the actors come forward and create a three part tableaux.)

Tableaux

*<u>TABLEAU 1</u> – **Thomas** is walking down the hallway holding his books. **Amber** sees him coming and points at him. **Billy** snickers to himself with his hand over his face, laughing at what is about to happen. **Lily** stands between **Billy** and **Amber**. She is not impressed with what is about to happen.*

*<u>TABLEAU 2</u> – **Thomas** is in front of **Amber**. He is in mid stride and **Amber's** has placed her foot to trip him. **Billy** points at **Thomas'** back and laughs hysterically. **Lily** looks away from the scene with disapproval.*

*<u>TABLEAU 3</u> – **Thomas** lies on his back on the floor. His books are all over the floor. **Amber** stands over him, laughing downward in his face. **Lily** has turned her head and snickers slightly. **Billy** looks toward the audience, laughing and pointing at **Thomas**. **Billy** invites the audience to partake in the "joke."*

Scene 1

(Thomas enters the stage quickly and takes a deep breath. He looks around to see if anybody else is there. He looks nervous. He looks out and sees the audience.)

Thomas

Oh Hi! I…ummm…I was just coming out to get some fresh air. Hardly anybody comes out here…that's why I like to be here. It's a good place to…just…breath.

My name's Thomas and this building is my school. I'm not a huge fan of school, but…ya know…it's alright!

When I'm not in school I like skateboarding and playing video games. Ya know…like …normal teenage stuff. Well, whatever "normal" means.

I…ummm...I also have Tourette Syndrome. I just wanted to let you know that. It seems to be the first thing that people notice about me when they meet me. They look at me kind of strange at first and then they say, "What's wrong with you?" Like that, in…like…a really mean voice…"what's wrong with you?" Wanna punch 'em in the face. I mean, I don't…but I wanna sometimes.

Oh wait…do you know what Tourette Syndrome is? It means I make a lot of sounds and I do movements that are…well…I guess involuntary!?! The sounds and movements are called 'tics.'

I'm not gonna do my tics for you…you'll know them when you see them! Like I said, it seems to be the first thing that people notice when they meet me…so…you'll see them…not like I can stop them…well I mean, I can kinda but…whatever…anyway, I don't wanna talk about it anymore…you'll just see it when it happens I guess. Oh, and by the way…when you see my tics, can you just…ya know…not make a big deal about it…please? I hate it when people point them out…I get it…I don't fit in…I'm not "normal"…I get it!

(Enter Amber looking at her phone.)

Oh crap…! That's Amber…what's she doing here? She's a total…

She's always buggin' me about my tics and makin' fun of me. She's also...like...the most popular person in school. Everybody loves her, and she walks around like she owns the place…so when *she* bugs me, *everybody* bugs me!

And she's friends with this girl…Lily…who's…well…you know…Lily's…ummm …well, she seems nice…but she hangs out with Amber, so she can't be that nice I guess…maybe…I don’t know. I don't really know Lily that well, but…ummm…even though she hangs out with Amber, I think she'd be a cool person to get to know.

(Amber looks up from her phone and sees Thomas. Thomas smiles awkwardly and waves at her.)

Thomas

Hi!

Amber

What’s wrong with you? Freak!

Thomas

(to audience) See what I mean…my tics are the first thing anybody sees!

(Thomas exits the stage.)

Scene 2a

(Amber is alone onstage. She sends a text message to Lily. ***“Lily, by the wall. Where R U?”*** *is projected on screen. Then puts her phone away. After a moment she looks at her phone a second time.)*

Amber

Come on Lily, where are you?

Video # 2 – The Bully

(Black screen where the title “The Bully” is written. We hear ambient music throughout this clip. Under the ambient music we hear Alan’s voice.)

Alan

Were you a bully?

(The youth speaking are pictured on screen.)

KO

Was I a bully?

Alan

Yeah!

KO

(smiling and releasing a loud breath) Yeah! There was this kid…ummm…this kid who was really annoying, and so I'd bug him.

(Screen fades out on KO and fades in on AC.)

AC

Ummm…if one of the *(uses air quotes)* "cool" people, like, in the popular clique said to, like, do this to someone, I would do it, 'cause I wanted to, like…I wanted to be accepted and fit in.

(Screen fades out on AC and fades in on MC.)

MC

(with a sheepish smile) I'm…I'm not going to say I haven't bullied people…but…

(Screen fades out on MC and fades in on CK.)

CK

You know how Billy sides with the other people, just, to be, like, popular, you know…that sort of thing. *(nods)* So…that's not me, but I mean…you know, he wants to be popular like the other kids, so he, kind of just, you know, does whatever he can to, I guess, try to fit in with the other people.

(Screen fades out on CK and fades in on MC.)

MC

There was a point where I was, myself, quite a big bully, and…I was sort of like Amber, where I would see people having differences and I wouldn't accept them for who they were.

(Screen fades out on MC and fades in on AC.)

Alan

(off camera) Tell me about Amber!

AC

If I didn't know anything about, like, what it's like to be, like, in her spot, then I would just think she's, like, a stuck-up snot. But, like, actually experiencing what it's kinda like…like in my previous years of school…ummm…I know I would always just try to fit in no matter what it would be. Like, I was self-conscious…so…

(Screen fades out on AC and fades in on MC.)

MC

I thought that it would be easier to get along with people if I acted unlike myself. I was quite an asshole. But I believe that I've changed for the better in that way. And now when I see bullying I try to…I try to prevent it. Before it was just, where, if I saw bullying I either left it alone or…added to the factor, where…and added to the bullying.

(Screen fades to black.)

End of video #2

Scene 2b

(Ambient music is still heard. Under the ambient music we see two characters – ***Tiffany*** *and* ***Nicholas*** *– step forward and walk around* ***Amber****. Both* ***Tiffany*** *and* ***Nicholas*** *are represented by the actors wearing neutral masks. Both are texting and pay no attention to* ***Amber****.)*

Amber

(waves) Hi Tiffany! Hi Nicholas!

(Neither Tiffany nor Nicholas speak or wave.)

Amber

(muttering to herself) 'Hi Tiffany! Hi Nicholas!'…I sound like an idiot…Like Tiffany and Nicholas are just gonna start up a conversation with me. *(Pretending to be Tiffany.)* "Oh, Hi

Amber! Me and Nicholas and Trent are going to the mall. You wanna come?"...What an idiot I am!

Come on Lily, where are you?

(Amber checks her phone again…puts it away and exits the stage in frustration.)

(Lily enters. She pulls out her phone and texts. ***"Amber, I'm by the wall, Where R U?"*** *is projected on screen. Lily looks around for Amber. Lily starts to exit and bangs into Thomas. Lily's phone falls out of her hand. Thomas bends to pick it up.)*

Thomas

….ummmm….

Lily

Thanks!

(Lily exits.)

Thomas

(After a moment of watching Lily leave the stage) That was Lily! Like I said, she seems nice.

Scene 3

(Still at the wall outside the school.)

Billy

(from offstage) Hey Thomas! Where are you?

Thomas

Oh crap! That's Billy. He's…like…my only friend, but he's exhausting! He's gonna wanna go do something…hang out at the mall or something. All I really want is to just be alone for a bit.

Billy

(Entering the stage) Thomas, I've been looking everywhere for you! Why are you hanging out by the wall alone? Let's go do something!

Thomas

I don't know…I think I just wanna…

Billy

No…don't say it! You just wanna be alone for a bit. No way! Come on! Let's go hang out at the mall.

Thomas

Why don't you go and I'll catch up with you in a bit!

Billy

No way! I know how this works…I go to the mall and you never show up. Let's just go to the mall…like normal teenagers…stop being retarded and let's go!

Thomas

(About to argue with Billy…then finally giving in) Sure…let's go to the mall!

(Billy starts to go and Thomas stops him by saying…)

Thomas

Billy, you know you shouldn't call me that word.

Billy

What…'retarded'.

Thomas

Yeah.

(Pause.)

Billy

Well…I guess I wouldn't have to if you didn't act like such a retard all the time! Come on Ticcy-ticcy, let's go.

(Billy exits.)

Thomas

(to the audience) He calls me 'Ticcy-ticcy' sometimes…ummm…it's kinda funny?!?! *(to Billy)* Alright, wait for me.

Discussion # 1

The discussion question posed at this moment in the play is…

If you were Thomas, What would your reaction to Billy's comments be?

Note that this question is not asking what the RIGHT thing to do would be – rather, it is asking what YOU would do if you were in Thomas' situation.

Video # 3 – Friendship & Fitting In

(Black screen. The title "Friendship and Fitting In" appears on the screen. Ambient music is heard. Over the ambient music we hear voices.)

Alan

(off screen) Do you think Billy is a good person…or…?

CK

Only if he wants to be.

Alan

What does that mean?

(black screen . . .)

Alan

(To KO) What do you think of Billy?

KO

I think maybe he's trying to fit in too but he can't like…he kinda feels bad for Thomas…so, I guess, he hangs out with him because he feels bad for him.

Alan

(To CK) Where Amber decides she's going to trip Thomas in one of the Tableaux at the beginning of the play, Billy's not really involved, but he doesn't stop it.

CK

Yeah, well I think it's just because he doesn't want to get, like, a bad vision from the popular kids, I guess.

MC

Especially the part, when, at the beginning, when Thomas gets tripped … ummm…that used to happen to me a lot in, like, in the hallways of my school and stuff like that…

Alan

Do you think that Billy likes hanging around with Thomas?

CK

If the, like, the popular kids aren't around and, ya know, him and Thomas are like, ya know, doing something, then I guess…yeah.

KO

I think Thomas thinks they're friends…I think that Thomas thinks that Billy is his friend. But Billy is just…I don't know…like, pretending a little bit, like bossing Thomas around.

AC

That's…that is pretty much like how everyday of my life is, cause I only really have one friend in this school, but whenever one of her friends comes by she just, like, totally ignores me…like I'm not even there.

KO

Cause I was, I don't know, teased of my tics and stuff. Like, the people, like, imitate my tics and stuff.

MC

Every school and every social place that I've been to has had some sort of bullying or antagonizing in some way, so…I do recognize a lot of that.

CK

But then it's more like a, I don't know, temptation to try to impress the popular kids.

Alan

Do you recognize Lily? Or is there anything about Lily that you say…hmmm…

KO

I don't know…cause she's hanging out with…ah…cooler people, like I was, when I was 7…8…and stuff.

(Screen goes to black.)

End of video # 3

Scene 4a

(At the mall. Amber and Lily are sitting in the food court. Neither is talking and both are checking their phones. Occasionally one of them chuckles, shows their phone to the other…the other chuckles and then returns to checking their own phone. After a time…)

Amber

OMG! I just saw on Twitter that Tiffany, Nicholas, and Trent are here.

Lily

So what!

Amber

So what…? They're going to see that movie *Ouiji*.

Lily

And…?

Amber

And…we should totally go too!

Lily

I don't know! I heard that movie sucks! Besides, Tiffany, Nicholas, and Trent are so stuck-up. If you don't agree with everything they say, they don't wanna hang out with you.

Amber

That's totally not true! They're hilarious! And Trent is so cute and totally single!!

Lily

So what? It's not like they're going to let you sit with them!

Amber

Who knows! Maybe we'll bump into them in the lobby and they'll be like… "OMG. You guys should totally sit with us!"

Lily

Yeah right! Like that's ever going to happen!

Amber

Come on! Be a friend and come to the movies with me. I'll buy popcorn and let you eat most of it!!

Lily

Fine! *(looking at her phone)* Hey look! *(showing her phone to Amber)* Billy's somewhere at the mall too.

Amber

And…

Lily

I'm gonna see if he wants to come to the movie. *(She begins to text him)*

Amber

(grabbing Lily's phone) No way! He's such an idiot…

Lily

Oh come on! Billy's awesome! He's the one who pulled that prank in Math class on Wednesday…Mr. Hardy was so pissed!!

Amber

Was that him? OMG…that was hilarious! *(giving Lily her phone)* OK…fine…invite him.

(Lily texts Billy. The text appears on the screen. ***"At the mall with Amber. Going 2 C Ouiji. Wanna go?"*** *The girls resume looking at their phones.)*

(On the other side of the stage, Billy and Thomas are seen hanging out in another part of the mall.)

Billy

(Picking up his phone) Hey, I just got a text from Lily. She's going to see that movie *Ouiji* and wants to know if I wanna go.

Thomas

Lily? How do you know Lily?

Billy

She's in a couple of my classes. She was having some trouble with chemistry and Mr. Jones asked if I'd help her out…you know…cause I'm so smart!

Thomas

Yeah right! Well, you can go to the movie if you want…

Billy

What do you mean? If I go to the movie you're going to the movie, and if you won't come to the movie then I'm not going to the movie, but I'm going to the movie 'cause I really want to see it, so that means you're going too. Case closed!

Thomas

I don't know…

Billy

Look if it wasn't for me dragging you along you'd be a total loser hanging out by yourself at home! Let's just go to the movie.

Thomas

No really, you should go…'cause Lily only…ummm…you know…she only asked you, so. Is this like a date or something?

Billy

Stop being weird! NO…it's not a date! Amber is going to be there as well. We're just going to hang out and see a movie…come on!

Thomas

Amber's going to be there? Oh God!! Now I'm totally not going!

Billy

Come on! Sure, Amber's a horrible, stuck-up human being…but other than that, she's nice! Besides, when the movie is on you don't have to talk to her, and once the movie's over we can make up an excuse why we have to leave…come on…I really want to see this movie.

Thomas

Alright, fine! Let's go to the movie!

Billy

Awesome! Billy and Ticcy-ticcy go to the movies!

(Billy texts Lily. His text appears on the screen. ***"I'm in! Thomas is with me. He's coming 2"****.)*

Lily

Billy's coming to the movie, and he's bringing that kid Thomas.

Amber

No way! That kid has a problem! He does that weird noise and he's always moving… just…weird…he's weird!

Lily

But Billy's already bringing him…so…ya know…it won't be that bad. You don't have to sit next to him, and when the movie's over we can just leave. Besides, he's…ya know…he seems like a good guy.

Amber

OMG! You totally have a crush on the weird kid!

Lily

Shut up! I do not!

Amber

Well, I don't care if you have a crush or not…just text Billy and tell him to ditch Thomas or not show up.

Lily

No, I'm not doing that!

Amber

DO IT!

(LONG Pause.)

Lily

Fine!

(Against her will, Lily texts Billy. Text appears on the screen. ***"Ditch Thomas! Meet us in the food court"****.)*

Discussion # 2

The discussion questions posed at this moment in the play are…

> **Why do you think Lily gives in to Amber?**
>
> **What could Lily lose if she doesn't give in?**
>
> **What could Lily gain by giving in to Amber?**

Scene 4b

(Billy looks at his phone and reads the text message.)

Billy

Oh…

Thomas

Is that from Lily? Where are we meeting them?

Billy

(Still looking at his phone) What…?

Thomas

Where are we meeting them?

Billy

Oh right…ummm…we're meeting them at the…ummm…the rink. But I have to use the bathroom first. Why don't you go ahead and I'll catch up with you.

Thomas

Why don't I just wait for you…I don't really know Lily…and Amber is…

Billy

No don't worry about it. They're expecting us so…you just head over there and I'll meet you in like 5 or 10 minutes.

Thomas

No…I really don't want to. I'll just wait here for you…

Billy

Alright fine…just…wait here!

(Billy makes his way toward Lily and Amber.)

Billy

Lily…glad I found you…this place is packed!

Amber

Good, you ditched your friend!

Billy

Who? Oh Thomas? No…he's not really my friend…yeah sure…I mean…we hang out from time to time…but I kinda feel sorry cause he's got nobody else to hang out with so…ya know…I let him tag along. Let's head to the movie.

(Billy, Lily, and Amber are about to leave when Thomas enters)

Thomas

(Shouting across the food court) Hey Billy! *(He catches up with them)* What happened to you? I was waiting upstairs.

Billy

Oh…ummm…I got a text from Lily after I left you and she said to meet in the food court. We were just on our way to find you…right everybody!

(Lily gives Billy a dirty look. Amber chuckles meanly and begins to leave.)

Amber

Come on! Let's just go! The loser can come too if he wants!

(Amber, Lily, and Billy begin to leave. Billy looks back at Thomas.)

Billy

You coming?

(Blackout.)

Discussion # 3

The discussion questions posed at this moment in the play are…

What *should* Thomas do?

What *will* Thomas do?

Are these two answers different? If so, why?

Scene 5

(On the screen we see the phrase "NEXT DAY AT SCHOOL")

(Thomas enters the stage quickly and takes a deep breath. He looks to see if anybody else is around. He looks nervous. He looks out and sees the audience.)

Thomas

Oh! Hi again! I'm just getting some fresh air…ya know.

Look…about the movie thing last night. Ummm…ya know…I make a lot of noise…and the movie theatre is so quiet…so…I just decided not to go. Probably wasn't a good movie anyway so…ya know…so I probably didn't miss much.

(Amber enters the stage. Checks her phone and then looks around. She sees Thomas.)

Amber

What's wrong with you? Freak!

Thomas

Why are you like that?

Amber

Excuse me!

Thomas

You're such a…why are you so mean?

Amber

Excuse me! Why are *you* like *that*? Why do you make all those noises?

Thomas

I have Tourette Syndrome…It's…I don't know…I can't explain it…

(Pause.)

Amber

(suddenly interested) Does it hurt?

Thomas

What?

Amber

The whatever thing you have…does it hurt? Like when you make noise and stuff…does it hurt?

Thomas

Yeah! Only when you make fun of me!

(Silence.)

(Tiffany and Nicholas enter. They walk around Amber.)

Amber

Hi Tiffany! Hi Nicholas!

(Tiffany and Nicholas stare at Amber and continue to walk away. As they walk away Amber looks rejected and alone. Thomas has been watching this from the side of the stage. Pause. Thomas steps forward.)

Thomas

(to Amber) Hey!

Discussion # 4

The discussion questions posed at this moment in the play are…

If you were Thomas, what would you do next?

If you were Amber, how would you react in this moment?

Does this moment change anything?

Performance Epilogue

Video # 4 – Moving Forward

(Black screen. Livelier ambient music is heard. The title "Moving Forward" appears on the screen. Over the music we hear Alan's voice.)

Alan

How were the sessions in general?

(As AC speaks, her interview is intertwined with still pictures and short video clips. The pictures and video clips were all taken during the creation sessions.)

AC

At first it was very awkward 'cause I wasn't really socializing before. And now that, like, I'm with people, like, real people who aren't…who don't put on masks and who know, like, how I feel…and like…they understand me. Now that I'm with people, like, that it's…I'm starting to open up a bit more to, like, people. People still give me a lot of anxiety and stress…but…yeah…it's been pretty good.

(The interview ends with a short scene of AC, CK, and KO playing a theatre game called, Ninja. All three teens are smiling. At the end of the scene, AC bends forward and laughs out loud.)

Alan

Somebody who has Tourette Syndrome, and they don't know how to deal with it…what would you want to tell them…about Tourette Syndrome?

CK

I wouldn't call it a mental disability. It's not something that really stops you from learning or anything. It's just, more like…how do I explain it…It's just…things that you do, ya know, on impulse, without, like, knowing. It's not only about, like, swearing uncontrollably…That's what people think. But, it's not just about that. If you see someone with Tourettes, you shouldn’t really make fun of them, ‘cause it’s not there fault. Ya know, they don’t want to do it, so…

Alan

Any advice you would give to Thomas?

MC

Now, he’s going through all of the bullying and through all of the rejection by the others at his school…I’d say, “eventually you’ll meet people who accept you for who you are, and who don’t care that you make noises or sounds.”

KO

I was like Lily, trying to fit in and stuff.

Alan

Would you say you’re like Lily now?

KO

(shaking her head) No, not like Lily now. I’m just hangin’ out with a bunch of really awesome weird people now. It’s really awesome! We talk about really weird stuff, and, like, really random stuff, and laugh at the stupidest things.

CK

It’s not a big deal, it’s like…some will think it’s life changing. It’s not really going to stop you from becoming whatever it is you want to be…unless you let it, at least…unless you let what people, you know, say, or whatever…you let it get to you. Yeah…it’s not really that bad of a thing. Doesn’t change your life that much.

MC

I’d say, “eventually you’ll meet people who’ll accept you for who you are, and who don’t care that you make noises…or sounds.” And I’d say that, “if…when you do find those people, you keep them and you try to keep a healthy relationship with them, and just throw the others out the windows.”

(Music fades on a photo of a white board with the quote “One who thinks he is wise is a fool, but one who knows he is a fool is wise” – Anonymous. Next to the quote is a hand drawn picture of a poinsettia flower.)

End video # 4.

CHAPTER 5

Reflections on the Process and Product

Introduction

As previously stated, the questions that guided this research were: What are the experiences of TS+ for youth aged 14-15? What experiences impact youth with TS+? What are the social ramifications of these experiences? How do these experiences affect the youths' social status and educational experiences? Through direct and indirect approaches, these questions were introduced at various points of the research study. The introduction of these questions into the research design informed and shaped the discussions that occurred during the sessions, as well as the theatre activities used to build and shape the final script.

Participants

In their article "Researching with Young People as Participants: Issues in Recruitment," James, Taylor, and Francis (2014) note that "recruitment of participants can make or break a research project and also influence the quality of the final outcomes" (p. 41). Here, James et al. allude to a negative correlation between poor participant recruitment and irreparable limitations to a study's design and outcomes. During the recruitment process for my research study, I encountered difficulties that led to low participant recruitment: interested participants who lacked the available time to participate in the research study; participants whose initial interest in the research study waned closer to the date of the first session; and participants who were interested in the research study, but unable to be involved due to personal challenges. In the days leading up to the first session (an introductory session with parents and youths) I was aware of only three potential participants – two youths who were keenly interested in the research study and one youth who expressed passing interest in participating in the study. To my relief, two additional youth participants showed up to the initial introductory session, meaning that the minimum sample size I had determined was required for the research study (which was four participants) had been met. After only four sessions, one of the participants self-selected out of the research study, making the sample size equal to the minimum number of participants required. This low sample size created a limitation within the research by decreasing the total experience with TS+ present in the room. While the small participant population *did* create a limitation to the research, the one participant's withdrawal *did not* prohibit the research from proceeding. In fact, the small number of participants allowed the group to create stronger bonds with one another, and based on my personal observation of the group, allowed participants to be more open and forthcoming during discussions. In this sense, the recruitment process helped to positively "make," or "shape" the research.

In addition to a small sample size, another limitation was placed on the research by the limited age range of the participants. While I initially sought participants between the ages of 13 and 18, the five interested participants present at the initial session were between the ages of 13 and 15. The greatest variation of age came from a participant who had turned 13 a week prior to the initial introductory session. Unfortunately, the younger participant self-selected out of the study after only four weeks, perhaps due to the age gap, which, in teen years, can seem exaggerated. By the fifth week the age range of the participants had narrowed to 14 to 15 years of age, and only one school grade (grade 9) was represented. In the end, a low recruitment rate and narrowed age range did influence the process. Questions still remain, for me, as to whether the group cohesion would have been as strong if there had been more participants and a larger age range. Would the experiences of TS+ that were expressed during the sessions have been richer with more participants or a greater age range? Would a larger group have inhibited or increased the engagement in each session's theatre-based activities? While limitations did exist due to the recruitment of participants, I believe that these did not ultimately limit the study's potential for transformation.

Relationship Building

In early sessions of the study, I had attempted to incorporate theatre based relationship-building activities into each session. My past experience as a high school drama teacher and theatre coach had demonstrated that such activities built bonds between participants, created trust amongst the group members, and provided grounding in the theatre creation process. While participants did build bonds between one another, these were not strictly due to the relationship-building activities I introduced. The activities I facilitated did not effectively serve to engage participants (who did not already know each other prior to their participation in the research process) in the theatre creation process, as I had witnessed in past youth theatre projects. I can speculate upon a number of possible inter-related reasons to explain this.

As there were only five participants in the early stages (and four for the majority of the research study), in such a small group, participants could not get lost in a crowd of bodies – participants may have felt inhibited to explore new theatrical activities that may have seemed "silly" to them. The phase of adolescence (aged 14-15) which corresponded to the study's participants' ages is said to present with many social and emotional struggles. First, an awkward tension between discovering "individual identity while still being accepted and fitting in" (Oswalt, 2010, para. 2) plays a large role in dictating social interactions. At the same time adolescents may "feel awkward or strange about themselves and their bodies" (McNeely & Blanchard, 2009, p. 12), adding another challenging layer to social interactions. For the participants, any actions or comments outside of what they saw to be "the norm" had the potential to jeopardize their ability to fit-in, so acting "silly" may have presented as too risky. The participants joined the research study with varying degrees of interest and experience in theatre and theatre activities, so their individual commitment to the (potentially) new theatre activities were varied, which may have limited the group commitment to the theatre activities introduced. Moreover, the challenge of sharing experiences about TS+ (perhaps for the first time) may have led to increased inhibition amongst the group. Participants' relative lack of engagement in the relationship-building activities may have been a complex combination of some or all of these considerations. Whatever the reasons, the participants' lack of engagement, which differed from session-to-session and person-to-person, was potentially one of the factors that shaped (and in some ways limited) the theatrical progress[10] of the research study. Nevertheless, by the end of the process trust, bonding, and friendship did develop amongst the participants.

Bracketing In

Lincoln and Guba (1988) make the claim that qualitative research is "a product of the interaction between site and researcher" (p. 8). In this way, the researcher and the research are entwined. As I am an individual with TS+, and a member of the Tourette Syndrome community in Edmonton, little attempt was made to "bracket" (Tufford & Newman, 2010)

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[10] Although, as outlined later in this chapter, the connotation of the word "progress" is debatable. The question must be asked 'whose version of progress are we moving toward?'

myself out of the research; instead I bracketed myself in (Norris, 2012). However, while I allowed my personal experience to influence the research, I was aware that my experience of having undiagnosed TS+ while growing up in a small town in Newfoundland in the 1980s most likely differed extensively from the experiences of the youth participants with TS+ in this research study. So, while I bracketed myself into the research, I was constantly "self-examining, self-questioning, self-challenging, self-critical, and self-correcting" (Lincoln & Guba, 1988, p. 8) in order to differentiate my personal experiences from the experiences of the youth participants. My experience, therefore, was offered as a means of enriching focus group discussions, or as a means of validating youth experiences from the perspective of an adult individual who had done significant personal and academic work to understand his own personal experience of TS+. I was aware of the differences between our experiences, and as such, my intention was to allow youth participants' experiences to emerge through group-directed discussion, and not in comparison to my experiences. I was careful to not allow my experience to become a standard by which all other experiences of TS+ should have been measured.

Data Collection and Analysis

In this section I focus my reflection more specifically on aspects of the process of generating and interpreting material with the youth. I entered this research with a didactic approach. This didactic approach was reflected in my initial research study design, which detailed three distinct phases that I imagined would occur throughout the process. The three distinct phases were:

Phase 1

Examination of video representations of TS+ – During this section, the participants and I would watch video documentaries of individuals with TS+. The videos were offered as prompts for discussion. A focus group discussion would occur after the video viewing. The discussion would compare and contrast the experiences shown in the video with our own personal experiences.

Phase 2

Exploration of emergent themes and patterns through the creation and rehearsal of a forum theatre play – Emergent themes and patterns discovered during the exploration of “self” (personal narratives) and “other” (narratives of others with TS+) in phase one were to inform the creation of a forum theatre performance.

Phase 3

Performance of the forum theatre – The community participation component of the research study was planned to end with two performances of a forum theatre (Boal, 1979) production. One performance was intended for an audience of university students and faculty members, and the other was intended for an audience of TS+ community members.

Early in the study I became aware that the progression between these three phases required more fluidity. Any attempt at creating precise delineations between these phases would have been an act of arbitrariness not reflected in the lived-experience of the sessions. The rigidity of the initial research design, viewed against the fluidity required to respond to the needs of the sessions presented what Aoki (2005) might have referred to as a tension between “curriculum-as-plan and curriculum-as-lived-experiences” (p. 159). In an identified need to move away from rigidity and toward fluidity (which might also be described as a move away from arbitrary design and towards experiential design (Aoki, 2005)), I loosened the precise delineations of the three phases of the research design.

As the research study progressed, oftentimes, session objectives were replaced with impromptu discussions. During one session, in which only one participant attended, the participant and I decided that a backdrop was needed for our performance. We decided that a brick wall would be an appropriate backdrop, and so the participant and I began to build the brick wall out of craft paper and paint. In later sessions, when participants’ engagement and energy was low, we would continue the work of painting bricks on the long strips of craft paper and discuss the participants’ weeks, or their interests, or whatever happened to be on their minds. It was during these sessions that we had some of the best discussions, when participants shared some genuine experiences about their TS+.

I wonder if the activity of painting the wall was able to elicit these genuine discussions because of the indirect nature of the approach, or what van Manen would refer to as “the activity passivity of doing nothing.” (van Manen, 2013). In earlier sessions, as an inexperienced researcher I felt the need to explicitly and directly collect as much “data” as possible. I would either audio record discussions or ask participants to write or draw their understandings of the experiences they shared. Such direct approaches, I see in retrospect, stifled the free flow of dialogue, as participants either did not want to record their experiences or did not want their experiences recorded by me. In contrast, the discussions of their experiences shared while painting the wall were never recorded, nor were they strictly limited to their experiences of TS+. These discussions ranged from popular music, to least favourite school subject, to favourite video game. Woven into the fabric of these discussions, the participants would sometimes discuss how TS+ impacted or was impacted by music, school, video games, or whatever other subject was begin discussed. These discussions provided indirect responses to the research question “what are the social ramifications of these impacts?” I learned to listen to these discussions as a mentor, not a facilitator. Sometimes I would explain how a certain experience related to my experience, or I would informally ask the group (never looking up from my work at hand) if they related to the shared experience.

In the end, these discussions informed the product of the script insofar as they provided character details, plot lines, and/or provided phrases to be used; however, these discussions were not recorded as pieces of “data” to analyze outside the confines of the performance. These discussions also embodied the potential for transformation. They provided participants with new-to-them perspectives on the experience of TS+, while also providing them with the emotional and mental space necessary to analyze these new-to-them perspectives in comparison with their own understandings of TS+.

Community Engagement through Popular Theatre Techniques

As previously discussed in this thesis, the use of various popular theatre techniques allows for a greater amount of audience/community engagement and dialogue than traditional theatre. These techniques to disrupt the “normal” theatre conventions in an attempt to shift audience members from passive watchers to active participants. Within the final performance of this research study, a number of popular theatre techniques were incorporated. These techniques (like Brecht’s alienation effect (Brecht, 1964)) were used to allow audience members to disconnect from being entirely immersed in the action of the performance, and instead connect the action of the performance to their own personal experiences and the experiences of other audience members around them.

In the initial conception of the research study design, I intended toward the use of forum theatre (Boal, 1979) as the model for the final performance. Forum theatre is a style of theatre that allows intervening audience members, or “spect-actors” (Boal, 1979), to come onto the stage in the role of the character whose struggles they understand and replay a scene to explore alternate possibilities. In theory, forum theatre aligned with the aim of the research, which was to increase audience understanding of TS+. However, in practice the theatrical demands necessary to undertake a forum theatre approach did not match with the skill-sets of the study’s participants. Early in the research study, forum theatre was dropped and was replaced with the broader approach of popular theatre, which brought with it a number of varying techniques to increase audience engagement.

Alternate audience seating. Another technique incorporated to disrupt the normalized theatre experience was the use of an alternate seating arrangement. Rather than audience members seated in rows that all faced the stage, which discourages audience members’ interaction with one another, the seating arrangement of this performance was altered to increase the potential for audience member interaction. An effort was made[11] to seat audience members in “pods” – a series of four chairs circling a black cube box. These pods were designed to draw people into discussion during the question breaks, as though they were seated around a table in a coffee shop.

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[11] I say, “an effort was made” because as the audience grew prior to the performance, there was a need to add more chairs to the back of the audience seating area. These chairs were placed in rows, as in a standard theatrical performance.

Video projections of participant interviews. In an attempt to capture the spirit of the research sessions that lead up to the performance, four short video sections (which included pre-recorded participant interviews interspersed with still images) were shown at various points throughout the performance. Much of the participants' experiences discussed during these videoed interviews closely mirrored the experiences of the characters in the performance. Through the juxtaposition of videoed interviews and theatrical representation, the audience was presented with a meta-understanding of the theatrical performance. While the performance remained at an analytically safe distance (i.e., fictionalized) from the audience, the mirroring of the fictionalized experiences within the videoed interviews provided community (i.e., real-world) connection to the performance. Here the videoed interviews served as a bridge between the fictionalized experiences portrayed in the performance and the real-life experiences of TS+.

Question breaks for audience. One technique that I used to engage audience was the provision of breaks in the performance to allow audience members to discuss the actions/behaviours/intentions of the characters. In these moments, I (acting in the role of "joker," which is Boal's (1979) word for performance facilitator) would stop the performance and re-iterate the situation that a specific character happened to find themselves in at that moment in the play. A question, which was meant to guide audience discussion, was then projected onto the screen.

While the intent of popular theatre is to encourage an active audience connection with the performance as opposed to a passive audience connection, the polite social conventions that surround theatre (such as not talking with fellow audience members during the performance) are strongly entrenched. By providing intentional breaks in the performance, the normalized theatre experience was disrupted and audience members were invited to discuss questions that had been specified for them. The "normal" theatre audience conventions were broken and audience members were freed to discuss the performance within the confines of this new (and communally agreed upon) theatrical convention.

Turn and talk. To invite discussion during the question breaks, a simple classroom teaching technique called *turn-and-talk* (theteachertoolkit, n. d.) was used. In the classroom, *Turn-and-talk* is a technique to provide students with an opportunity to "turn" to their classmates and "talk" about their thoughts, opinions, or ideas on the curricular material being discussed at that moment. As a teaching technique, *turn-and-talk* "permits all students to participate in discussion, rather than only a few students participating in a class-wide discussion. All students are able to process new learning while engaging in meaningful conversation with a classmate" (theteachertoolkit, n. d., para. 1). As a technique to engage a theatre audience, *turn-and-talk* allowed audience members to comment on and, in turn, potentially gain knowledge or understanding of character situations by discussing with fellow audience members. Through *turn-and-talk*, audience members were invited to shift from the passive role of "watcher" to a more active role of "participant."

While the "data" that arose from the audience during turn-and-talk discussions was not collected as a part of this research study, conversations started in *turn-and-talk* moments had potential to continue beyond the sharing-celebration. One individual (a mother of a child with TS+) who had attended the sharing-celebration with her family told me that a week after the performance her family was still discussing a thread of a conversation that was started during a *turn-and-talk*. This “ripple” (Norris, 2009, p. 42) of performance moving into community is a site for potential transformation that demonstrates the impact that popular theatre can have on community dialogue.

Reflection on some techniques. The popular theatre techniques incorporated in this performance were intended to allow audience members the opportunity to engage with the performance as active participants rather than passive observers. To varying degrees, these popular theatre techniques were successful in their intended purpose. However, while there were observed successes that derived from these techniques, there were also areas that provided opportunities for reflective growth for me as a facilitator.

Although an effort was made to configure the audience seating into “pods” to accommodate audience discussion, additional chairs were added in rows at the back of seating area, to accommodate for the larger than anticipated audience. Whereas a “pod” might have drawn audience members who did not know one another into a discussion, the arrangement of chairs in rows had the potential to exclude audience members from all discussions. While the purpose of the *turn-and-talk* was to build understanding through audience inclusion, and build awareness from group understanding of the performance, the seating arrangement may have excluded some audience members from this discussion.

To further elucidate the example above, here are two scenarios that occurred on the day of the event. In the first scenario, a friend of mine entered the space, greeted me, and took her seat alone in one of the “pods”. A while later, another friend arrived with her daughter, and, playing the role of host, I introduced the second friend and her daughter to the first friend and they sat in a “pod” together. During the *turn-and-talk* sections of the performance, I noticed that all three were involved in discussion. In the second scenario, a friend of mine entered alone, greeted me, and took her seat alone in a row at the back of the space. During the *turn-and-talk* sections, I noticed that she was not in discussion with anyone else, and instead individuals on either side of her had turned out to discuss with other audience members. Of course, this is not to say that she *was* being excluded as she may have deliberately chosen not to involve herself in any of the discussions around her. However, these two scenarios do point to the potential unintended impact of the seating arrangement and the *turn-and-talk*. While the intended benefits of both the seating arrangement and the *turn-and-talk* were to promote inclusion, in these particular scenarios the potential for exclusion is also present. Upon reflection, I see that a brief (and emotionally safe) theatre-style icebreaker activity might have bonded the audience members to those around them, thus overcoming the isolation of individual audience members that may have resulted from the seating arrangement.

Balancing Preconceived Notions and New Philosophies

As a first-time community-based researcher, I learned many lessons throughout the process of this research study. The framework for many of these learned lessons came through the search for balance between the process of theatre creation using a community-based participatory model and my internal desire to produce a theatrical product that was both engaging and entertaining to an audience. Putting community-based research into practice involved a continual search for balance, a personal desire to engage with and disrupt my personal schema and biases, and an exploration of what it means to “be” part of a community.

Having had experience as a high school drama teacher, as well as experience working with youth in schools as a guest artist and theatre coach, I entered the research with preconceived understandings of what it meant to facilitate a youth theatre creation project. However, my preconceived understandings were, at times, in opposition to the theoretical and philosophical underpinnings of community-based participatory research (CBPR). While attempting to balance my preconceptions of theatre creation with the new-to-me tenets of CBPR, I was also creating a piece of popular theatre – a theatre style that closely mirrored my previous theatre creation projects as well as the tenets of CBPR, but presented me with a theoretical framework that, at times, proved challenging. While attempting to reconcile these areas – my preconceived understandings of theatre, the new-to-me tenets of CBPR, and the theoretical framework of popular theatre, I was also keenly aware (and constantly reminded) that I was working with a vulnerable group of youth on a topic that presented both psychological and emotional challenges to all participants, including me. Many of the lessons that I learned throughout the research process came from my attempts to balance preconceived notions within new-to-me theoretical frameworks.

The tension between my past theatre creation experience and the new-to-me CBPR framework became evident during the rehearsal phase. In past youth theatre creation projects, my role was that of drama instructor/director. In this role, one of the key aspects was creating a product that was both entertaining and engaging to an audience. While creating popular theatre within the CBPR framework, my role shifted from that of drama instructor/director to that of research facilitator. The most important aspect of this new research facilitator role became engaging youth participants in the research and allowing them to find their voices within the process. The challenge that I found in this role-shift was reconciling a direct approach, which I believed to be necessary as a drama instructor/director, with an indirect approach, which I believed to be necessary as a research facilitator. This challenge presented me with an internal tension. On one hand, as research facilitator I knew that allowing youth participants the space and time to explore and to find their voices within the process was a necessary component of the research, but on the other hand my experiences as a drama instructor/director made me keenly aware of the impending deadline of the final performance and I felt compelled to push participants toward creation of a product that would be both entertaining and engaging for the audience.

A third role that I played during this research was that of mentor. As an adult with TS+, I saw the role of mentor as an opportunity to model positive coping strategies for my motor and vocal tics as well as my associated disorders. Part of this modelling involved being open and frank with youth participants about my personal experiences with TS+. Whereas the previously mentioned role of drama instructor/director concerned itself with the product of the research, this mentor role sided with the research facilitator role's grounding in process. However, unlike the research facilitator role, which grew from a new (and at times uncomfortably new) theoretical framework, the mentor role grew from an internal and personal understanding of some of the participants' struggles with TS+. Within the research the mentor role became increasingly important. This role provided the necessary connection with youth participants for us to continue to build understanding throughout the study. The mentor role also provided a familiarity with the theatre creation process, which the research facilitator role did not offer me. Through reflexive engagement with these three roles, I was able to find familiarity within the process and a focus for the study, all the while keeping the notion of "product" present and alive in my mind.

Tensions between process and product. The tension between process and product framed many of the challenges I faced throughout this research study. After witnessing a session that was particularly direct (and directed), my thesis advisor, Dr. Diane Conrad, put words to my inner struggle. In an email communication she wrote, “The important thing is that their voices are heard, not so much the quality of the performance” (personal communication, February 15, 2015). My first response to this statement was a defensive thought: Of course their voices are heard. The script comes from their voices! After reflecting on Dr. Conrad’s comment, I began to understand that the script represented the youth participants’ *words* – a frozen representation of our past discussions. In taking the direct approach of working toward a theatrical product, I was, in effect, stifling the youth participants’ ability to connect their *voices*, which occur in any given “present” moment, with their *words,* which are representations of their past (even if recent past) thoughts. In this way, the performance was moving towards becoming a representation of the youth participants’ past experience of TS+, as opposed to an expression of their present experience with TS+. In a subsequent email in the same thread, Dr. Conrad made this point clear, stating, “In my experience working with youth, if we focus too much on the product it can become an oppressive experience” (personal communication, February 16, 2015). In placing too much focus on the product, had I run the risk of creating an oppressive experience for youth participants? Was my direct approach stifling their ability to use their voices in the sessions? Did they feel they were being heard in the sessions? During the sessions following Dr. Conrad’s visit, these questions guided my approach to the research and theatre work. However, my internal conflict between drama instructor/director, facilitator, and mentor continued throughout the entire research study.

Didactic versus participatory. I entered this research study with a didactic approach – I had decided the agenda of the sessions, the flow of the sessions, and the overall "product" to be achieved, all based on the desire to "instruct" participants, and eventually community-members, about TS+. This didactic approach greatly jeopardized my ability to promote a participatory environment. Luckily, I became aware of the tension between my didactic approach and my intended participatory approach early in the study, and as a result I focused on shifting away from the didactic/teaching structure. Instead of teaching (which can carry with it the connotation that the "teacher" has knowledge that the "learner" does not have, and therefore the "teacher" must teach and "learner" must learn (Friere, 1970)), which runs contrary to a participatory approach, I focused on allowing the participants' emerging patterns to influence the flow of the sessions. Rather than "teaching," I attempted (with varying degrees of success) to shift my approach to that of a facilitator – presenting participants with suggested tasks accompanied by loose deadlines with the faith that all "learning," which I was unable to plan for, would arise from the completion of these tasks[12].

Re-structuring the sessions away from a didactic approach and into a participatory approach also challenged my personal schema of "success" in a theatre-based project. The shift in approach led to a looser structure than I was used to. Within this loose framework the participants' engagement levels continued to wax and wane (as it had throughout the study), and as a result there were fewer and fewer outwardly visible signs of (what I deemed as) "progress." This challenged my schema of "success" that I had attached to a youth theatre project. Should success have been measured by the quality of the performance, or rather by the transformational potential of the research sessions? In reflecting, I have come to see that

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[12] As I re-read this sentence, I am reminded of the tension present between didactic and participatory. Even in those moments when I had attempted to move away from "teaching," I still (misguidedly) placed focus on the planned "learning."

there is no right answer to this question. Rather, (like many of the dichotomies that I had originally set up for myself) within a theatre-based approach to research, “quality of performance” and “transformational potential of the research” lie on a spectrum, determined by the many varying factors of the research (i.e., participants desired outcomes, intentions of the study, duration of the study, input of the participants/researcher, etc.)

Reflections on internal tensions. Through reflecting on, and intending toward community-based research tenets such as community involvement, co-creation of knowledge, and engagement with experiential knowhow (Green, Daniel, & Novick, 2001; Hall, 2005; Flicker et al., 2007; Israel et al., 1998, 2001), the teaching and theatre methodology in this research study continually evolved throughout the sessions. While the re-structuring and re-focusing that occurred throughout the study was necessary, it challenged my personal schema of the structure of a youth theatre project. This challenge of my personal schema allowed for increased understanding of my personal biases, which valued product-oriented projects over process-oriented projects – biases that had shaped (and potentially continue to shape) my entire theatrical teaching/facilitating practice up until that point. While this study provided me with the ability to examine my personal biases, I do not see the internal struggles around these biases as being resolved. These struggles will continue to influence future projects; however, I have come to see these struggles as beneficial to a project as opposed to detrimental.

Transformational Potential in the Creation Process

Looking back, I am aware that the potential for transformation existed not in the multitude of voices expressing experiences of TS+, but rather in each participant's connection to other participants, the participants' abilities to build ownership of their experiences by sharing them in the safety of the group, and these shared experiences being witnessed, honoured, and mirrored back to individuals via group interaction. For example, during one session, as participants were putting away art supplies, I noticed one participant become overly engrossed in the task of putting crayons back in the box. Recognizing this pattern, and knowing that the participant was experiencing an incident of OCD, I gently asked the participant if I could help. The participant, recognizing what was happening, light-heartedly explained that she needed similar shades of crayons to be next to each other in the box. Another participant, having witnessed this event commented that he sometimes had similar incidents of OCD. Other participants chimed in about their experiences with OCD, and a spontaneous discussion about each other's past OCD experiences occurred, all while the crayons were being neatly organized in the box according to shade. In that moment, all participants' experiences were witnessed by each other, honoured as real events worthy of discussion, and mirrored back in the shared experiences of other participants. Through this witnessing, honouring, and mirroring process, the youths' shared experiences were not viewed as "strange" or "weird," as perhaps they had been viewed by others in the past. Instead, these experiences were discussed as just another behaviour in the list of behaviours that made each of them unique. This is one of the many examples where the potential for transformation was tangible within the room, not due to the multitude of voices within the discussion, but because experiences were being witnessed, honoured, and mirrored.

This impromptu OCD discussion also demonstrates the difference between direct and indirect approaches to research. In earlier sessions, the participants and I had sat in a circle, I had placed my tape recorder in the middle of the circle, and I had asked direct questions about their experiences of TS+. While participants had shared experiences during this direct questioning approach, the sharing did not grow into dialogue, but rather became simply a list of experiences that had occurred to various participants. In the indirect (or rather impromptu) OCD discussion, the experiences expressed by participants built on the shared experiences of others. A collective understanding of the experiences of OCD had been constructed. In this discussion (and other indirect/impromptu discussions that occurred throughout the sessions) a true response to the research questions, “what is the experience of TS+ for youth aged 14-15?” and “what experiences impact youth with TS+?” was being represented.

The Effects of Attention Deficit Hyperactivity Disorder on the Research Study

A tool I have often used with success in past youth theatre projects is a written outline of the daily activities that is shared with participants. This is a process that I used in early sessions of this research study. I created PowerPoint slides to outline the activities for the day – these slides were then shared with participants. The rationale for creating these slides was to promote participant autonomy over the theatre creation process by allowing them to understand the direction and flow of each session. I believed this would allow participants to regulate their own working pace. In addition to increasing participant autonomy, experience had taught me that by sharing the daily plan with students, I, as teacher/facilitator, would be held accountable (to varying degrees) to the outline – my own ADHD brain would be prevented from following its naturally tangential thought patterns. This need to anchor the

ADHD brain provided me with further rationale to share session outlines with participants. Early in the research study, all participants had disclosed having ADHD as an associated disorder of their TS+. In working with youth with ADHD in the past, I had learned to "chunk" information into easily process-able pieces, which the PowerPoint outline did. All of these past experiences provided me with a rationale for providing session outlines for participants.

My belief that participants would be able to cognitively process each "chunk" of information before transitioning to the next "chunk" of information led me to offer the sessions' outlines in written form. However, through post-research reflection, and upon further research into ADHD and executive function disorders (which research has connected with ADHD) (Solanto, 2011; Sjöwall, Roth, Lindqvist, & Thorell, 2012), I have learned that the issue with ADHD is not always a problem of understanding or remembering "chunks" of information, but rather a problem of transitioning between the "chunks" of information (Schachar, Tannock, & Logan, 1993; Merkel et al., 2000). Therefore, even when an outline of the agenda was presented to participants and reviewed as a group, participants often expressed confusion about the steps of the process. As the sessions progressed, and I continued to witness this seeming inability to process the written agenda, my sharing of a plan became less and less structured – from a detailed step-by-step plan displayed on a PowerPoint slide; to a loosely structured plan written on a whiteboard; to a list of tasks that *needed* to be accomplished during that session; to a list of tasks that we would *try* to attend to throughout the session; to a list of tasks that we would try to accomplish before the sharing-celebration. This progression is another representation of the research study's shift from "curriculum-as-plan," based on progressing toward a product, to "curriculum-as-lived-experience," (Aoki 2005, p. 159), based on a loose list of suggestions that framed a process of examining and exploring experiences of TS+. This shift from product-oriented to process-oriented thinking even impacted the naming of the capping event of our study. Instead of referring to the capping event as a "final performance" we referred to it as a "sharing-celebration," which emphasized the desire to "share" the outcome of the process, as opposed to "perform" a product that had been created.

In the end, while the ever-looser list of suggested tasks led to slower progress of our theatre creation, it did lead to increased participant engagement, increased comfort in discussing personal experiences of TS+, and increased socialization between participants. This realization led me to question my understanding of the term "progress." Could painting a brick wall and discussing music and video games with participants be considered progress? To answer this question, I first asked another question: what are we progressing toward? To answer this second question, I reviewed the over-arching research question of this study: *What are the experiences of TS+ for youth aged 14-15?* In reviewing this foundational question, I realized that "progress," as it was interpreted in this research, was a clarifying of the experiences of youth with TS+, and while I had framed this question with thoughts of certain kinds of experiences, hearing about the participants' interests and activities in and out of school was helping me understand their experiences. This awareness did not fully appease my internal drama instructor/director who was focussed on progressing toward a theatrical product, but it allowed me to understand each session as progress within the framework of the research study.

Social Rejection – Internalized Loneliness

Throughout the research study, many discussions arose surrounding the topic of social rejection leading to internalized loneliness. The notion that social rejection from peers (and in some cases from teachers) can lead an individual with TS+ to internalize the belief that they deserve the scorn of others (and thereby deserve to be left alone) was a common theme in Scott's (2006) documentary *Teenage Tourettes Camp*, and was also eluded to in other videos from Tourette Canada's *@Random* series (Golding & Bobula, n. d.; Croswell, n. d.).

The creation of these internalized feelings align with Diamond's notion of "feedback loops" (2007, p. 62) and demonstrates the unique pattern of these feedback loops for individuals with TS+. The customary pattern of a feedback loop states that an individual puts forward a behaviour in the form of an action, this action is either affirmed or negated by others within the society, depending on the feedback received (affirmation of negation) the individual's action is reinforced or adapted (i.e., continued or changed). The feedback loop for an individual with TS+ is similar in the first two steps – the individual with TS+ puts forward an action (in the form of a tic), the action is either affirmed or negated – however, from here the feedback loop is altered. If the action (in the form of a tic) is negated (as it often is) the individual with TS+ doesn't have the standard option of "continue" or "change", the option now becomes "continue" or "suppress." Continuing with the tics, which is the natural instinct of the individual with TS+, becomes an internalized act of defiance in the face of social cues, whereas suppression of tics creates stress, which in turn creates more tics. Both of these choices – "continue" or "suppress" – divert the act of ticcing away from an external, societal dialogue based on social cues and instead places it as an internalized struggle for the individual with TS+ – internalized defiance or internalized stress. Whether an individual with TS+ decides to "continue" or "suppress" the resultant pattern creates the breeding ground for internalized feelings of guilt and loneliness.

After watching the video *Neil* (Croswell, n. d.) in one of the research sessions, the participants began a discussion about social rejection and internalized loneliness. In the video, Neil says "You can also get bullied for it as well…like you can get made fun of for Tourettes. You may get called 'retarded,' or 'special.' And they may just be joking, but it can cut deep" (Croswell, n. d., 2:05). After watching this video, one participant noted, "if I'm being called [retarded] directly it…would either make me really angry or really sad." This discussion, and the comment about how such name calling would make one participant feel, informed the creation of the character of Billy in the final script. In the script after Billy calls his friend, Thomas, "retarded," Thomas says, "You shouldn't call me that word." To this, Billy replies, "Well…I guess I wouldn't have to if you didn't act like such a retard all the time!" As was mentioned by the participant, the character of Thomas was saddened by this response. Due to this, and other social rejection, the character of Thomas eventually chooses not to follow his friends to the movie, using the excuse that it "probably wasn't a good movie anyway so…ya know…so I probably didn't miss much." The study's participants mirrored the fictitious character's feelings of loneliness brought on by social rejection.

Another example of social rejection leading to negative internalized feelings was evident during a session in which a segment of the documentary *Teenage Tourettes Camp* (Scott, 2006) was shown. The youth participants were asked to draw or write about any personal connections they had made between the experiences of the teenagers in the video and their own experiences. During the drawing/writing component of this session, a number of interesting patterns emerged concerning overlapping feelings of anger and sadness. The five teenagers in the documentary also commonly expressed these feelings.

In analyzing some of the drawings produced during this session, a pattern of internalized sadness and externalized anger emerged. For example, the question, *"What's with you?"* in Figure 1 appears to come from an external voice, perhaps questioning the sounds and/or movements that the individual makes. This could be an example of the social rejection felt by the drawer. It was external voices such as this one that inspired the attitude of the character Amber in the final script. Whereas the question in Figure 1 comes from an external voice, the comment *"I need friends"* in Figure 2 is an internalized voice. Figures 1 and 2 can be seen to represent a cause and effect – societal rejection leading to internalized loneliness.

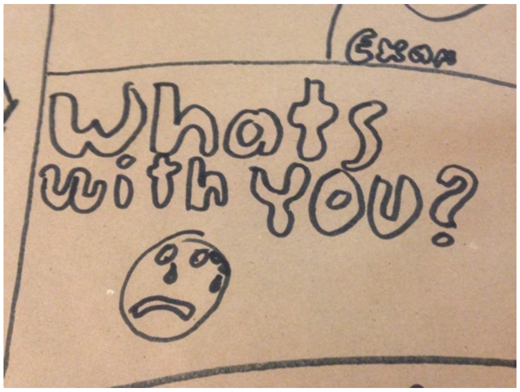

Figure 1 – What's With You?

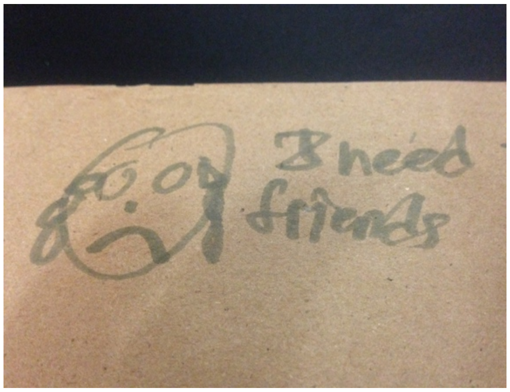

Figure 2 – I need friends

Feelings of rejection and loneliness were not the only emotions to emerge from this drawing/writing activity. Figure 3 follows the pictorial theme of crying faces that is present in Figures 1 and 2. However, the defience present on the face in Figure 3 (i.e., forrowed brow, snarled lip, direct one-eyed stare), combined with the image of a hand with middle finger raised and the assertion that the speaker is "okay," demonstrates internalized anger overlapping with sadness. As in Figure 2, the feelings in Figure 3 are internalized – sadness turned to anger. The anger of Figure 3 carries over into Figure 4, which directs the anger at a personified TS+, perhaps seeing TS+ as the reason for the societal rejection present in Figures 1 and 2.

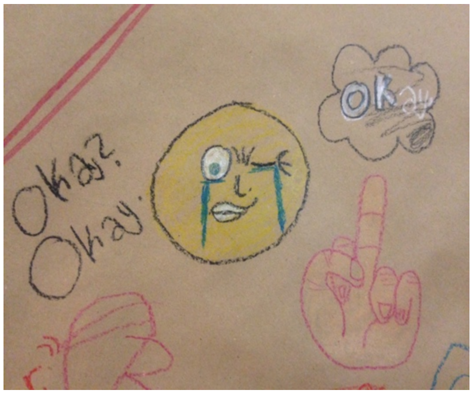

Figure 3 – Okay? Okay.

Figure 4 – Fuck you tourettes

Resonance and Dissonance between Theatrical Scenarios and Personal Experiences

Through an exploration of the resonances and dissonances between the youths' own experiences and the experiences of the characters in the play, this research allowed youth participants the opportunity to reflexively and critically examine their personal experiences of TS+ in contrast and comparison to the experiences of the others with TS+. Drawing on the work of performance studies scholar Richard Schechner, Conrad (2004), explains the potential for reflexivity present in popular theatre as "the player exist[ing] simultaneously in two worlds: as a character inside the experience of the 'as if' world and as an actor evaluating the situation from the outside, within the real world" (p. 16). Through an embodied connection in this "liminal pedagogical space" (Conrad, 2004, p. 16), in which the potential for reflexivity was present, youth participants of this study were able to better understand their experiences in the real world through comparison with the "not me" (i.e., experiencing dissonance between the characters' motivations and intentions and the participants own values) and the "not not me" (i.e., experiencing resonance between the characters' motivations and intentions and the participants own values) (Schechner, 1985, cited in Conrad, 2004, p. 16).

Two examples of this dissonance and resonance occurred during the video-recorded interviews, which became part of the final sharing-celebration. In one example, a character was introduced as a "bully," but the bullying behaviour was later revealed to be that character's way of coping with low self-confidence and insecurity. In reflecting on this character during the interview, the participant playing the role explained: "If I didn't know anything about what it's like to be in her spot, then I would just think she's, like, a stuck up snot." With this statement, the participant reflected on past perceptions of individuals that the participant may have thought of as a "bully," while also highlighting that this past perception of the "bully" arose because she "didn't know anything about what it's like to be in [their] spot." With these words the participant described the "not me" – a dissonance between the character and her own identity. She continued by adding, "But, actually experiencing what it's kinda like [by playing the role in the performance]…like, in my previous years of school…ummm…I know I would always just try to fit in no matter what it would be. I was self-conscious." With this statement, she linked her past perception of the "bully" (the dissonant "not me") with her emerging awareness of what might lead a bully to become a bully, which she then reflectively paired with her own past behaviour. Through embracing the dissonance present in the "not me" (by performing the role of the fictitious character), the character resonated with her, allowing an understanding of the "not not me" (the recognition of the motives behind the fictitious character's actions). This resonance created the potential for the participant to empathize with the bully, thus presenting a potential site for transformation to occur.

Another participant demonstrated resonance and dissonance created through character reflection. When asked whether she recognized anything in her character, she responded, "I don't know…cause she's hanging out with…ah…cooler people, like I was, when I was 7…8…and stuff…I was like [the character], trying to fit in and stuff." Here we see the participant recognize the "not not me" aspects of the character – a recognition of the resonance between the character and the participant. When asked whether she was like the character now, she responded, "No, not like [the character] now. I'm just hanging out with a bunch of really awesome weird people now. It's really awesome!" In this instance the she identified the "not me" aspects of the character – a recognition of the dissonance between the character and herself. In this instance, the site of transformation is identified by the participant, who then has the potential to reflexively build on her understanding of her present self in relation to her past self.

In these examples, the participants were able to recognize dissonance ("not me") as well as resonance ("not not me") between themselves and the characters. Their awareness of the dissonance and resonance provided a response to the question "how does TS+ impact the youth's social status?" In both cases, the participants acknowledged that their past desires to "fit in" had created tensions between being popular and upholding personal values.

Evaluation

One technique for evaluating audience engagement and transformation that I undertook was informal post-sharing-celebration discussion with audience members. (I informed audience members that any comments they made during the post-sharing-celebration talkback might be used as part of my evaluation of the project and in my thesis.) The use of post-sharing-celebration discussion with audience members as evaluation had benefits and drawbacks. One benefit was that specific moments of the play were still fresh in audience members' minds, and as such, audience members were able to support comments with specific examples from the play. For example, one audience member, who attended with a friend whose child had TS+, told me that prior to the play he knew little about the social issues experienced by individuals with TS+. After witnessing the play he had enough understanding to begin a conversation about TS+. In discussing his newfound awareness, he referred to a moment in the play when the lead character's best friend "playfully" calls the character "retarded." For this audience member, that moment helped him better appreciate his friend's child's social experience. The ability to recall and discuss a specific moment from the play was important for the audience member as it supported his comments. As a piece of evaluation, his comments (and his ability to link them to specific moments) confirmed for me the performance's ability to represent the truth (credibility) (Lincoln and Guba, 1985, 1986, 1988) of the experience of TS+ as well as the performance's ability to connect to other contexts (transferability) (Lincoln & Guba, 1985, 1986, 1988), in this case to his friend's child's experiences.

While there are benefits to using post-sharing-celebration discussion as "data," this method of evaluation also presented drawbacks in that the authenticity of the data I collected must be examined with a certain degree of scepticism. In my experience, as a theatre artist (and theatre-goer), I have learned that comments made by audience members directly after a performance can be skewed by the desire to provide overly positive feedback (regardless of the audience member's true impression of the performance), particularly when speaking with the play's director or actors. Rarely (if ever), have I been involved in a performance that was greeted with negative comments from audience members directly after the performance. Usually, individuals wishing to share negative or "constructive" feedback will wait until a later time. In the case of this research study, many people were congratulatory and offered comments such as "well done" and "good work" after the performance. However, while these comments were uplifting and showed the positive support that the community provided for the research study, they did not necessarily demonstrate the performance's ability to successfully represent a first-person experience of TS+.

I also aimed to evaluate the efficacy of theatre as a tool for transformation for participants. For this, I evaluated participants' experiences through observation and self-reporting. Early in the study, participants were asked to maintain a written account of their experiences of our sessions through journal entries. During the first journaling session, some participants stated that it felt like school. One participant completely refused to write anything, while other participants wrote only a few sentences. By the third session, all participants expressed a desire not to write a journal entry. As the journaling process was creating a school-like experience for participants, and this school-like experience was detracting from the participants' engagement in the sessions, the journaling at the end of each session was replaced with drawing and doodling, which was later replaced by the invitation to share thoughts about the session in a check-out circle..

As a general note, I noticed that toward the end of the research study, participants were more willing to share their personal experiences with TS+ than they were earlier on in the study. This increased willingness to share experiences may have been due to participants gaining a level of comfort within the session and familiarity with other participants. This may have provided them with a safe environment to build self-advocacy skills that could be practiced in the safety of the room. As well as participants' increased willingness to share, there was also an increased comfort level and confidence while sharing. Toward the end of the research study, I noticed that the group check-ins, which started almost every session, were becoming longer as participants were more willing to share events of their weeks, regardless of the events' connections to TS+. In addition, toward the end of the research study, youth displayed more social engagement with one another, as well as a willingness to interact with me.

While these witnessed phenomena *are* indications of participant transformation throughout the study, the question remains whether these transformations were directly linked to the research study. The study did bring participants together and provided them a safe environment to build/strengthen self-confidence, self-advocacy skills, and socialization skills, but did these skills lead to increased social engagement in the real world? Or were individuals' experiences outside of our sessions having an impact on them? It is impossible to know and futile to attempt to trace the causes of transformation through such complex human interactions. The validity of a research study such as this comes not from being the sole cause of transformation within participants, but rather in providing a safe environment in which personal transformation may be sparked.

Attempting to measure transformation is a problematic endeavour in any case, and particularly within the abbreviated time period of a Master's research study. While there were perceived signs of increased confidence and self-advocacy skills amongst the participants of this study, the transformational potential of this study may not have fully emerged for participants during the research study's allotted time period. This is not a comment on the efficacy of this research study, but rather on the latent nature of transformation. Fritjof Capra (2007) expressed this latent potential for transformation in his foreword to David Diamond's book *Theatre for Living: The Art and Science of Community-based Dialogue*. In discussing the multiple experiences that may impact a social dynamic, Capra states that, "one can never direct a living system; one can only disturb it" (p. 17). In connection with this research study, I am aware that the participants (as living systems) could never be directed to increase confidence, self-advocacy skills, or socialization, but in *disturbing* the participants' normalized patterns and themes, the potential for transformation may have been introduced.

Another way in which measuring transformation can be problematic is due to the multiple ways which transformation may be expressed (e.g., increased confidence, improved self-advocacy skills, increased socialization skills, etc.). Moreover, such transformation may take the form of easily witnessed external changes (e.g., increased socialization, explicit advocacy, etc.), or not easily witnessed internal changes (e.g., increased internal sense of confidence, increased understanding of internal feelings, etc.).

While transformation may be difficult to measure, it can be witnessed, and this witnessing can have powerful ramifications, as was evidenced during the talkback portion of the sharing-celebration. The mother of a participant tearfully expressed the transformation that she had witnessed in her son since he had been taking part in the research study:

> I know first hand, having M. . . at home, since he's begun this, he's coming around quite a bit and I'm very proud of him *(beings to sob)*…sorry…and he holds his head up higher, and he's got a lot more confidence today that he didn't before…and I'm

> just very proud of this whole experience. He's a different boy here today than he was before you began.

So, while it may be difficult to measure the amount and the type of transformation that occurred within this participant, this mother's experience is a testimony to the fact that transformation had occurred.

For my part, the true evaluation of the youth participants' emerging self-confidence and self-advocacy skills was demonstrated during the talkback that followed the sharing-celebration. During the talkback, I witnessed four youths with TS+, who had struggled to voice their experiences with TS+ at the beginning of the research study, sit in front of a room of 60-70 individuals from the Tourette Syndrome and University of Alberta communities and discuss their personal experiences. I witnessed one participant gently and caringly address a younger audience member with TS+ to explain her experience. I witnessed another participant, who had suffered anxiety attacks during our early research sessions openly and confidently answer questions from the audience. Even though it is difficult to quantitatively measure transformation, the juxtaposition between the timidity of the youth during early sessions and the bravery demonstrated during the sharing-celebration talkback provided evidence that this research study had contributed to some form of transformation in the youth participants.

Epilogue

Over the past decade or two, there have been a number of mental health initiatives that have countered the pervasive belief that mental health is somehow connected to personal will, attitude, or behaviours. The goal has been to create awareness and understanding that mental health issues are not due to a person's habits, laziness, or unwillingness to get over it. While social discussions normalizing mental health issues are occurring, the belief that mental health issues are due to personal will, attitude, or behaviour is still present in society. Even more devastating than the presence of these beliefs is the internalization of these beliefs by individuals with mental health issues.

I am an individual with TS+, and as such, in addition to motor and vocal tics, I also have Attention Deficit Hyperactive Disorder, Obsessive Compulsive Disorder, Anxiety Disorder, and at times Neurological Storms (or what are sometimes called Rage Attacks). These are my neurological realities and I am cognitively aware that they are not due to lifestyle choices, lack of motivation, or a bad attitude. However, the difficulty for me (and many other individuals who I have spoken with as a TS+ advocate) is not in admitting that I have neurological disorders associated with TS+, but rather overcoming the internalized belief that if I eat the right foods, get the right exercise, get enough sleep, avoid alcohol and caffeine, avoid stress, and learn better relaxation techniques that I can overcome any and all of my associated disorders. Due to this internalized belief, when I have difficulty focusing, or I spend 15 minutes arranging and re-arranging my desk before leaving my office at the end the day, or I am overcome with an anxiety attack, I somehow feel shame and regret – it is my fault because I ate the wrong food, drank a second cup of tea, stayed up too late watching a movie, have not exercised in several days, etc. Ultimately, I have internalized the belief that my mental health issues are my fault, and as such these neurological issues come with guilt and shame.

The events of the day. To demonstrate this internalization process in action, I will highlight the events of the day leading up to the community sharing-celebration that was the culminating event of my engagement with the research participants.

The performance component of the sharing-celebration was to occur at 2:00 p.m. Audience members were scheduled to arrive at 1:30 and youth participants and other community volunteers were scheduled to arrive at 1:00. I arrived in the event space at around 10:00 a.m., and, while experiencing a great deal of stress, had plenty of time to prepare the space. Around 10:30 a.m., my wife (who is a theatre artist and TS+ community volunteer) and I were moving a greeting table into the hallway. The door shut behind us. A key-card was needed to gain re-entry, but my key-card was locked inside the room along with my cell phone, wallet, and all other forms of ID. What followed was two-hours of panic as we tried to re-enter the room. At 12:30 p.m. we finally re-entered the room, with only 30 minutes to prepare for the youth participants and community-volunteers.

Almost immediately after the door locked I started having an anxiety attack, characterized by blurred vision and tunnelled hearing (imagine listening to your surroundings through long tubes). In that moment, I believed that due to the stress of the situation I was having a brain aneurysm. Anxiety attacks can be physically and mentally draining, as this one was, but after the attack I re-focussed on entering the room. After several failed attempts at entering the room, my frustration had reached a point where I was overcome with a neurological storm (or rage attack). I smashed my watch against a brick wall, jumped up and down, and screamed. To the outside world, I was having a temper tantrum. Inside the experience, the normally calm and rational part of me was aware that my actions were extreme, but I was powerless to stop them from occurring. I cannot recall another time in my life where both an anxiety and a rage attack happened with such ferocity or in such a short time span. I was physically and mentally exhausted. Thanks to the clarity and composure of my wife, we made it back inside the room and quickly continued to set-up the space.

My duty during the sharing-celebration was to play the role of organizer, host, master of ceremonies, discussion facilitator, researcher, and perhaps most importantly, role model to the youth participants (who admitted to strong feelings nervousness). I did not accomplish all these tasks to the best of my ability. I was unclear in explaining to the audience the structure of the sharing-celebration, I barely covered the ethical considerations, I paced and fidgeted while onstage, and I was unable to answer questions that, on any other day would have been second nature to answer. Throughout the sharing-celebration I was in active survival mode, using breathing and relaxation techniques to quell the anxiety creeping up my neck. The work of the youth participants during the sharing-celebration was truly brave, but in my mind, my attacks and my lack of focus were my fault, and they jeopardized the success of the sharing-celebration.

Why share this story? My initial instinct was that sharing my personal mental health experience of that day would be seen as my excuse to atone for what I saw as poor performance on my part. However, after reflecting on the day, I realized that the reason I needed to share this experience was because I felt I could not (or should not) do so. I had internalized the belief that it was my fault that I gotten locked out of the room, and that I was unprepared for the session. I had internalized the belief that my mental health experience was my fault and that I had jeopardized this research study due to negligence.

I am aware that many individuals with mental health issues have internalized similar beliefs, including perhaps some of the youth participants with whom I worked. This epilogue serves two purposes. First, to voice this internalized guilt and shame that I, and others with mental health issues, may feel, so that these thoughts may begin to be examined in the open. Second, to provide another layer to the experience of the sharing-celebration. While audience members were watching a fictionalized narrative of true-to-life youth experiences of TS+, a real-life experience of TS+ was simultaneously being played out on the stage.

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